

CHILDREN'S RESILIENCY, ADJUSTMENT, AND COPING: CANCER-RELATED,
FAMILY CONTEXT, AND WITHIN-CHILD FACTORS

A Dissertation

by

KATHERINE MICHELE NEWTON

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

August 2007

Major Subject: School Psychology

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ABSTRACT

Children's Resiliency, Adjustment, and Coping: Cancer-Related, Family Context, and

Within-Child Factors. (August 2007)

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This study identifies variables that influence childhood psychosocial adjustment to cancer diagnosis and treatment by examining the illness-related factors of physical functionality, severity of illness, relapse status, and stage in treatment; family context factors of parenting stress and family psychosocial risk; and within-child factors of personal resiliency. These factors were assessed among 37 children with leukemia or lymphoma, one of their caretakers (29 mothers, 7 fathers, 1 grandmother), and one of their medical care providers (14 physicians, 22 nurse practitioners, 1 physician's assistant) through a one-time completion of questionnaires.

Results revealed that several significant associations were found between child adjustment and independent variables. Specifically, the child's age at the time of diagnosis, the time since his/her diagnosis, his/her gender, the caregiver's stress related to parenting an ill child, and the child's personal resiliency were each identified as factors related to child psychosocial adjustment. Directionally, children who are diagnosed at a younger age, or who have been in treatment for a longer period of time may be at risk for psychosocial adjustment difficulties. Female gender and increased

frequency and difficulty of parenting stress may also be risk factors associated with maladjustment. Personal child resiliency, as measured by presence of social and emotional strengths, can be protective in terms of preventing adjustment difficulties.

DEDICATION

To Lexy and Noah

ACKNOWLEDGMENTS

I would like to thank my committee co-chairs, Dr. Bill Rae and Dr. Cyndi Riccio, for their advice and support throughout this process. There were many times over the course of this study when I doubted my ability to complete it. Your tolerance of my “ambitious” time lines and dreams for what this project could be was a significant factor motivating me to keep going. I appreciate the knowledge and expertise of committee members, Dr. Rob Heffer and Dr. Vic Willson, for their guidance in developing and finalizing this study. Thanks also to my friends and colleagues and the department faculty and staff for making my time at Texas A&M University a great experience.

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I would especially like to thank all of the children, families, and medical personnel who were willing to participate in the study. Your courage and determination to help other families through your participation was remarkable. There was more than one family who agreed to participate and specifically did not wish to receive an incentive, stating that providing information that may help other families was enough reward. Their selflessness through the crisis that is childhood cancer is inspiring.

Finally, infinite thanks to my family for their encouragement. Mom, Dad, Becky, and Michael, you have been so validating of me during times when I felt frustrated or discouraged. Your words have always motivated me to keep going and realize my goals no matter the barriers. To my husband, Jared, I cannot tell you how much I appreciate your patience and support over these seven long years! With the completion of this degree, I am excited to be moving into the next chapter of our lives together. To Jared's family, your experiences with childhood cancer have been the motivation behind this study and my career in pediatric psychology. I admire your strength and commitment to other families experiencing the same trauma that you have faced, and hope that through my work, I can be a small part of this cause.

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CHAPTER I

INTRODUCTION

There has been a great deal of research over the last 50 years examining factors that relate to the psychological adjustment of children with cancer. As treatments for childhood cancer have improved, examination of children and families' abilities to cope and adjust to the lengthy demands of treatment has replaced psychology's role in assisting families in preparation for the child's death. With this shift, researchers have found that living with the now *chronic illness* of cancer has important implications for children's emotional, behavioral, and social functioning.

Previously developed theoretical models have hypothesized that there are several factors related to chronic illness that may impact these areas in children's lives (Wallander & Varni, 1992, 1998). Specifically, there may be factors related to the illness itself that can impact the child's life in terms of physical limitations or changes in appearance. There may be familial factors that have a direct impact on the child in terms of how the child's parents or siblings are adjusting to the child's illness and how the family is coping and utilizing available resources. There may also be personality factors within the child him- or herself that would be expected to impact his or her ability to adjust to a chronic illness.

Research conducted over the last 20 years has generally demonstrated that children with cancer show surprising resilience in the face of their illness and treatment.

This dissertation follows the style of *Journal of Pediatric Psychology*.

In fact, most findings indicate that rates of psychopathology among children with cancer are generally equivalent to rates found in healthy children. As a result, another recent shift has emerged in psychological research and practice with this population. New lines of investigation attempt to identify factors that put children and families at risk for development of psychological difficulties as well as protective factors. With this information, care can be provided to families in a preventative manner, with the most resources going towards families who are at greatest risk. Based on theoretical models derived through previous research, there are certain risk and protective factors that may be examined further.

Previous research examining illness-related factors and their impact on children's adjustment have largely been equivocal. While many studies have demonstrated limited effect of physical functionality or severity of illness on adjustment, others have indicated that a relationship does exist, albeit an indirect one (e.g., physical limitations lead to social withdrawal, which causes adjustment problems). Recent reviews of the literature indicate that high degrees of functional impairment are correlated with poorer psychological functioning (Patenaude & Kupst, 2005). Research has also demonstrated within-child factors that can impact psychosocial adjustment to cancer, including the child's age and degree of perceived stress. These factors have received the least attention in the literature, and reports of child functioning are often based solely on parent report, which can be biased. Finally, research has demonstrated unequivocally that for children, parents and other family members play a key role in the development and utilization of coping strategies in the face of crisis or trauma. Specifically, parental

distress and additional family stressors have been shown to be significantly related to child adjustment.

Because of the vast number of factors to consider, it is important to provide practitioners in this area with a working model of assessment to inform intervention. Previous research has largely been theoretical, or has examined only specific parts of the general model. In order to inform treatment, it is important to gather data in all of these areas within the same sample. There appears to be a reciprocal interaction between the ongoing illness-related, individual, and systemic changes and individual/familial adjustment. In other words, **the diagnosis of childhood cancer creates a fluctuating process of adjustment to change over time rather than a distinct event.** Wallander, Thompson, and Alriksson-Schmidt's (2003) model fails to account for the factor of time, and this seems to be an important variable to consider in addition to the illness-related, family context, and within-child factors when examining childhood cancer processes.

There are multiple other gaps in the research that should be examined further to provide practitioners with a more accurate picture of these issues. In terms of family context factors, findings have been limited by measurement issues (e.g., parent report only, usually mothers, use of measures not designed for pediatric populations). In addition, findings have generally demonstrated typical psychological adjustment, but there has not been examination of individual resiliency factors in this process. Finally, results from previous studies are equivocal regarding the impact of illness severity and physical functionality.

Carefully designed studies that identify the emergence and maintenance of outcomes could add critical information (Vannatta & Gerhardt, 2003). Study of cancer-related, family context, and child resiliency factors and their relationship with psychosocial adjustment over the course of chronic illness will assist us in conceptualizing childhood cancer as a context-dependent process rather than a distinct event at diagnosis. Viewing coping and adjustment in this manner, while utilizing a data set from a single sample of children and families provides psychologists working with pediatric populations with information that will serve to inform psychosocial treatment.

Given the current state of the literature and the call for more research in family systems and child resiliency in pediatric psychology, the purpose of the present study is to examine the relationships between illness-related factors, family context, and child resiliency as guided by portions of Wallander et al.'s (2003) model. Specifically, this study will examine illness-related factors, family context factors, and child resiliency as variables related to child adjustment to cancer, and will attempt to examine child adjustment to cancer as a process over the course of illness as defined by relapse status and stage in treatment. Specific research questions to be addressed are:

- 1) *To what extent are illness-related factors (e.g., severity of illness, physical functionality) related to child adjustment (e.g., internalizing and externalizing symptoms, adaptive behavior)?*
- 2) *Does relapse status (i.e., presence versus absence of relapse) significantly affect child adjustment (e.g., internalizing and externalizing symptoms, adaptive behavior)?*

- 3) *Does the child's stage of treatment (i.e., induction/intensification versus maintenance) affect child adjustment (e.g., internalizing and externalizing symptoms, adaptive behavior)?*
- 4) *To what extent is family context (e.g., parental distress, family adjustment) related to child adjustment (e.g., internalizing and externalizing symptoms, adaptive behavior)?*
- 5) *To what extent is child resiliency related to child adjustment (e.g., internalizing and externalizing symptoms, adaptive behavior)?*
- 6) *To what extent does parental distress moderate the relationship between parent report of child adjustment and child report of child adjustment?*

Based on the current literature, it is predicted that illness-related factors will be significantly and negatively correlated with child adjustment as reported by parent and child (i.e., as health problems increase, adjustment will decrease). It is hypothesized that those children who have experienced one or more relapses or who are in the induction or intensification phases of treatment will evidence greater adjustment difficulties in comparison to children with no relapse or those in maintenance phase as reported by parent and child. It is expected that the frequency and difficulty of parental emotional distress will correlate with the child's adjustment as measured by parent and child report. Further, it is also expected that the overall psychosocial stress of the family as reported by parent will correlate with child adjustment as reported by parent and child. Lastly, it is hypothesized that those children who demonstrate greater overall personal strengths

(or resiliency) as measured by parent and child report will also demonstrate better overall adjustment as measured by parent and child report.

This analysis is unique in that it uses a systems perspective and focuses on children's resiliency. In other words, the analysis looks at systems-level factors that can predict both children's emotional/behavioral distress/problems as well as psychosocial adjustment/functioning. The answers to the questions listed above will help to conceptualize some of the factors involved in the psychosocial adjustment to childhood cancer. It is important to understand the relationships between illness-related, family context, and child resiliency factors in order to inform psychosocial treatment with pediatric populations. If pediatric psychologists have a good understanding of these factors, they will be in a better position to work collaboratively with behavioral medicine teams to ensure that each family's needs are met in such a way that the best possible adjustment and functioning of children with cancer can be predicted. In other words, it will provide direction to the field that will inform practice.

CHAPTER II

LITERATURE REVIEW

Living with a chronic illness has important implications for children's emotional, behavioral, and social functioning. Examining these variables is important given the impact of chronic illness on children in the United States. About 10-20% of the general child population has a chronic illness; about 10% of these (1% of the total population) are considered to be severe (Thompson & Gustafson, 1999; Wallander et al. 2003). Wallander et al. defined a chronic physical condition as one that interferes with the child's daily functioning more than three months per year, causes hospitalization for more than one month per year, or is expected at time of diagnosis to cause either of these conditions.

Children and families coping with chronic illness generally experience some form of psychosocial adjustment. This "adjustment" may be defined in terms of a broad range of levels of functioning, including both clinical maladjustment, as well as variability over time and situation (Wallander et al., 2003). Good adjustment is generally manifested in the form of developmentally-appropriate, normative, healthy behavior, while maladjustment may be identified in the form of behaviors that are age inappropriate and normatively defined as pathological or clinical. For example, it would be "normal" for a child to demonstrate some sadness, tearfulness, and questioning of their situation, but these behaviors would become "pathological" if they are severe, persistent, or begin to interfere with daily activities (e.g., wanting to stay in bed all day, crying uncontrollably for no apparent reason, decreased interest in previously enjoyed

activities, thoughts of hopelessness). Thompson and Gustafson (1999) described “psychosocial adjustment” as an umbrella term that includes the dimensions of psychological adjustment, social adjustment, and school performance.

Adjustment to chronic illness may be dependent on the environmental and emotional stressors experienced by children and families as a result of the illness. For example, families dealing with chronic illness may be affected by: the burdens of daily care, economic constraints, frequent medical care appointments and hospitalizations, fears and anxieties related to the often unknown nature of diagnoses and treatments, anxieties related to the pain and discomfort experienced by chronically ill children, and negative influences on normal child development, including changes in the child’s education and social relationships (Thompson & Gustafson, 1999; Wallander et al., 2003). How families adjust to these stressors may differ greatly. The developmental course of chronic illness and how it is impacted by changes in biological and treatment factors seems to imply that psychosocial adjustment to and coping with chronic illness is a dynamic process that children and families experience with cognitive, emotional, and behavioral changes over time.

Chronic illness can be diagnosed at various ages, and usually involves management of symptoms without the expectation for permanent cure. However, each chronic illness has a very different biological process, and treatment regimens vary greatly. Due to the variability in symptoms and treatment of different illness, and the changes that occur within these factors over time, it is possible that chronic illnesses have a tendency to follow a developmental course that is unique to each child and

family. Most chronic illnesses impact children and families over an extended period of time. With this time, multiple changes occur within the child's life that may impact his or her overall adjustment. For example, their physical symptoms may subside, or may be well-managed by medications/other interventions, making their physical daily functioning virtually "normal." Or, their illness may become suddenly worsened, causing them to have an extended hospitalization, which causes them to miss school, and thus miss academic and social development opportunities. As children continue in the course of their illness, there will likely be periods of ups and downs that may impact their adjustment differently at different times. Various researchers have emphasized that child and family functioning should be viewed on a continuum over time. Literature in the areas of stress and coping also emphasize a model that considers the context of time, as well as the severity and duration of stressors (Quittner, 1992).

Kazak (1989) indicated a need for longitudinal studies that relate disease activity, child characteristics, outcome, and family variables. The importance of studying these variables over time was emphasized due to the evolving nature of both families and course/treatment of illnesses (Kazak, 1989). As children's adjustment waxes and wanes, this may impact the stress and functioning of their family members. For example, a mother who sees her child as having difficulties in his or her adjustment may feel stressed about this, causing some sadness or anxiety. Her child may then pick up on this stress and feel more stressed about the situation. Or, conversely, a parent who maintains positive coping strategies and hopefulness may be observed by his/her child, thus

affecting the child's adjustment in a normative way. Thus, there appears to be a reciprocal interaction between the child and family's adjustment.

There are a variety of factors that have been shown to correlate with the adjustment of children experiencing a chronic illness. These factors may be categorized into three different types: factors related to the illness, within-child factors, and social-ecological factors. Factors related to the illness may include: condition severity, functional status, prognosis, condition type, and duration. Factors specific to the child may include: gender, temperament, distractibility, child coping methods, self-concept, IQ, age/age of onset, social support, resiliency, and cognitive processes (e.g., perceived stress, perception of physical appearance, and stigma). Finally, social-ecological factors may include: maternal adjustment, marital and family adjustment or conflict, family support or cohesiveness, parent ratings of life stressors, family functioning, family psychological resources, parental stress, and peer relationships (Wallander et al., 2003).

Various researchers have organized these factors into theoretical models, and one of these, by Wallander and Varni (1992), is particularly helpful in conceptualizing the issues involved (See Appendix I). Their Disability-Stress-Coping Model was later adapted by Wallander et al. (2003; See Appendix II). This model originally grouped the factors that may predict child adaptation to chronic illness into two categories: risk factors and resistance factors. After the model's adaptation, Wallander et al. used a non-categorical approach, conceptualizing condition parameters, functional independence, psychosocial stress, social-ecological factors, and intrapersonal factors as variables that directly impact child adjustment. Stress processing was also defined as a variable that

indirectly impacts child adjustment as mediated by psychosocial stress. This model will be used to inform the conceptual foundation of this paper, and will be described in more detail. However, more updated terminology will be used to describe the constructs and will be defined subsequently.

Adjustment to Chronic Illness

Psychological research in the area of pediatric chronic illness dates back to the 1950's. Early research was highly qualitative (Phipps, 2005) as the field was new and information was being gathered in order to determine the questions that needed to be answered. As researchers learned more about their target population, research shifted to quantitative methods, and there was a significant amount of literature produced in the 1970's and -80's that assisted psychologists working in pediatric settings in learning about the children and families that they assisted. These early researchers were not sure if it was appropriate to study groups of chronically ill children across diagnoses, or whether analysis should occur separately given a possible difference in factors contributing to psychological status as a function of the disease/disability.

Several models conceptualizing the issues involved in coping with chronic illness have emerged in the field as a way to assist in answering this question. In 1984, Rolland's model included three aspects of the illness across several dimensions: 1) illness-related factors, including onset (acute versus gradual), course (progressive, constant, or relapsing), and outcome (degree of incapacitation); 2) phases of the natural history of the illness; and 3) family systems variables (Barakat & Kazak, 1999). Pless and Perrin (1985) also examined features that can assist in categorizing or distinguishing

chronic illnesses from each other, including prevalence, mobility-activity, course of illness, age of onset, cognitive and sensory functioning, visibility, and time required for diagnosis. Kazak and Christakis (1996) revised Rolland's (1984) model, and included the four dimensions of onset, course, outcome, and degree of incapacitation, as well as five aspects of impact on the family: unpredictability, disability, stigma, monitoring, and uncertainty in prognosis.

The question of method for analyzing these factors remains throughout more recent research. Garstein, Short, Vannatta, and Noll (1999) analyzed three different options to determine which may be most helpful and appropriate including: discrete disease, noncategorical, and mixed models. Discrete disease models emphasize focus on each chronic illness in isolation from others as the issues involved in the treatment and illness itself are assumed to be specific to that disease and different from others. The noncategorical model indicates that there are common factors among all chronic illnesses that can be examined across disease types. This model is supported by Wallander and Varni (1998). Finally, mixed models blend features of the discrete and noncategorical approaches, and recognize both differences and similarities across illness types (Garstein et al., 1999). Results of Garstein et al.'s investigation revealed that a noncategorical approach appeared most appropriate in examining the impact of chronic illness on children in that comparisons of emotional and behavioral adjustment were found to be similar across groups of children with Juvenile Rheumatoid Arthritis (JRA), hemophilia, sickle-cell disease, and cancer. At the same time, Garstein et al. (1999) stated that there are a significant number of factors that may impact an *individual* child's

adjustment to chronic illness. This finding may best be summarized by Pless and Perrin's (1985) earlier work, indicating that emphasis at either extreme (categorical or noncategorical) is not helpful because families with chronically ill children have both specific and common needs (Pless & Perrin, 1985). There is a need for continued systematic evaluation of these factors.

Despite this dispute and differences in analysis methodology, the majority of research conducted in the late 1980's indicated that children facing life-threatening illnesses generally reported low levels of psychopathology, including sadness and depression (Kazak & Nachman, 1991). In fact, literature reviews from the time indicated that chronically ill children generally demonstrated patterns of psychopathology similar to that in the general population of physically healthy children (Drotar & Bush, 1985). Thus, it was deemed more important to examine the factors that contribute to children and families' adjustment or non-adjustment, than to compare families affected by chronic illness to those who are not, as the latter approach emphasizes deficits in the first group (Kazak, 1992a; 2001).

Several conclusions were made by Drotar and Bush (1985) based on assessment of the current research at the time:

- 1) No one adjustment pattern is associated with chronic illness,
- 2) The psychosocial strengths of chronically ill children outweigh their difficulties,

- 3) Chronic illness is a stressor that can contribute to increased mental health risk, but typically only in association with other variables, such as family adjustment,
- 4) Disease severity does not have a simple relation to mental health adjustment, but may be related through mediating or moderating factors,
- 5) Conditions involving sensory or motor impairments entail a higher risk for mental health problems,
- 6) Specific illnesses appear to have selective effects on various dimensions of psychological functioning, in accord with the life experiences imposed by symptoms and treatment,
- 7) The family context emerged as a critical influence on children's mental health, and
- 8) School and peer contexts are also important influences.

Despite the finding that children with chronic illness do not demonstrate significant psychopathology, it was commonly agreed that they are faced with a variety of stressful circumstances that require coping responses and may benefit from intervention (Compas, Worsham, & Ey, 1992; Kazak, 1989). These children are largely “at risk” for development of emotional and behavioral difficulties, indicating a need for preventative work (Kazak, 1992a; Wallander & Varni, 1992). Thus, research is needed to identify the children who are at particular risk or who demonstrate protective factors. In order to do so, it was important to identify factors that may place children at risk for developing adjustment problems (Gerhardt, Walders, Rosenthal, & Drotar, 2004). For

example, early findings indicated that certain functional areas may be affected by chronic illness, including cognitive functioning and academic performance, social-emotional functioning, and family functioning (Garrison & McQuiston, 1989).

Literature reviews during the 1990's continued to echo the sentiment that children with chronic illnesses were vulnerable to maladjustment, but more specific findings were lacking, partially due to inconsistency in measurement of constructs and absence of a theoretical framework (Kazak & Nachman, 1991; Wallander & Varni, 1998). "Ultimately, it seems as if a model that identifies a core group of variables related to adjustment and coping across illnesses, with specific factors that would contribute positively or negatively to coping with specific types of conditions, is necessary" (Kazak, 1992a, p.103). In order to examine this issue further, Wallander and Varni (1998) completed a review of the literature, which focused on theory-driven work, programmatic efforts at identifying predictors of adjustment, and research that has clinical applicability. The seminal works analyzed in this review revealed that children with a chronic illness typically demonstrated more adjustment problems than comparison groups. However, only a minority of children with chronic illnesses were considered "maladjusted" (Wallander & Varni, 1998). Some researchers argue that differential coping and adjustment may depend on the child's developmental stage during diagnosis and treatment (Magrab, 1985; Patenaude & Kupst, 2005). In summary, childhood illness appears to function as a stressor that, in combination with other variables, may contribute to increased risk, but is not the sole cause of adjustment difficulties (Schuman & LaGreca, 1999).

Chronic Illness and Family Context

Also during this time, integration of research, theory, and practice between the areas of health and family psychology was in its very early stages (Kazak & Nachman, 1991). Kazak (1989) introduced a “family systems and social ecological model for understanding coping and adaptation in childhood chronic disease” (p. 25). A family system is conceptualized by Patterson (2002) as two or more individuals and the patterns of relationship between them. Family relationship patterns are considered multidimensional, with several processes characterizing the relationships, including, but not limited to, cohesiveness, flexibility, affective and instrumental communication, and behavioral control (Patterson, 2002). Families serve several functions for its members and society, including family formation and membership, economic support, nurturance and socialization, and protection of vulnerable members (Patterson, 2002). Kazak’s (1989) model emphasized that several factors are important in understanding the impact of chronic illness on children and families, including the child’s attributes, perceptions, understanding, and reactions, as well as parental stress related to the daily demands of parenting a child with special needs, and the social isolation of families (Kazak, 1989). These themes can be found throughout Kazak’s writings (1992a, b, c). This emphasis on families was again highlighted by Kazak in 1997, and a call for research that frames questions from a family/systems orientation was encouraged. In addition, Kazak recommended that data be included from more than one member of the system. She stated that research in pediatric chronic illness should aim to capture diversity. It should broaden the boundaries of systems. She encouraged researchers to maintain a

developmental, normative, competency framework, and stated that research should orient towards pediatric practice (Kazak, 1997).

Chronic Illness and Child Resiliency

Another recent movement in the research and practice areas of pediatric psychology is “positive psychology” (Seligman & Csikszentmihalyi, 2000). Our society has a history of focus on the causes of *disease, deficits, and behavioral problems* (Patterson, 2002). As part of this society, psychological research is a reflection of this trend. Historically, the field of general clinical psychology focused on patient’s difficulties and problems, with intervention addressing remediation only after the onset of psychopathology (Kazak, 1989). However, in the 1970’s, the field gradually moved away from a problem-focus and began addressing concerns more preventatively, as well as analyzing the causes for staying healthy in the face of risk and adversity (Patterson, 2002). The concept behind this shift is now referred to as “resilience.”

Over the last 20 years, there have been calls made to researchers regarding the importance of examination of factors that contribute to the resiliency, strength, and hardiness of children and families coping with chronic illness rather than the previous focus on maladjustment (Drotar & Bush, 1985; Gerhardt et al., 2004). This approach is referred to as “strengths-based” rather than “deficits-based.” The strengths of these children and families are viewed in three different ways by Gerhardt et al.: hardiness, resilience, and enhanced functioning. Hardiness indicates that the child and/or family experiences no changes in their functioning over time, but remain in a state of overall positive adaptation. Resilience indicates that the child and/or family experiences an

initial period of decreased functioning due to the illness, but then recovers over time. Enhanced functioning indicates that the child and/or family experiences overall improvement in functioning following onset of the illness. Conversely, families may experience maladaptive patterns of functioning that may include: stable maladjustment and declining adjustment.

This shift towards “positive psychology” seems appropriate in the realm of pediatric psychology given the research finding that children with chronic illnesses are “at risk” for development of psychological problems, but often do not present with clinically significant psychological disorders above what would be expected in non-ill populations (Kazak & Christakis, 1996). It is equally important to understand the *protective factors* that allow children and families to adjust to chronic illness (Gerhardt et al., 2004).

However, Richardson (2002) conducted a review of recent articles published in the *Journal of Clinical Psychology* and determined that most interventions and inquiry focus on examining the nature and cure of various *disorders*. Therefore, while psychological researchers, practitioners, and other helping disciplines may recognize the need for a positive shift in theory and practice, this shift has not fully occurred. In order to identify the full spectrum of adaptive and maladaptive pathways, researchers are being called to move away from the exclusive use of deficits-based measures, and to add positive outcome measures as well (Gerhardt et al., 2004).

Research examining the strengths of families coping with childhood chronic illness have indicated generally higher scores on standardized measures of child and

family functioning (Patterson, 2002), which is contrary to the expectation that the risk of a chronic illness would lead to difficulties in child and family functioning. This high functioning may indicate that some families already had the protective capacity to manage the significant risk (i.e., “hardiness” or “resilience”), or that families developed the protective resources needed to respond to the stressor successfully (Patterson, 2002), similar to Gerhardt et al.’s (2004) “enhanced functioning.”

Childhood Leukemia as Chronic Illness

One chronic illness affecting children and families is cancer. Childhood cancer is estimated to have been diagnosed in about 9,510 children under the age of 15 in the United States in 2005 (American Cancer Society [ACS], 2007). This chronic illness is the leading cause of death from disease in children under the age of 15, with approximately 1,585 deaths in 2005 (ACS, 2007). The types of cancer typically seen in children vary greatly from cancer in adults, and include leukemias, brain and other nervous system tumors, lymphomas (lymph node cancers), bone cancers, soft tissue sarcomas, kidney cancers, eye cancers, and adrenal gland cancers as the most common types (ACS, 2007). Due to significant advances in the treatment of these cancers, it is estimated that 79% of children diagnosed with cancer will survive five years or more (ACS, 2007). This is a major increase since the 1970s when this 5-year survival rate was less than 50%.

Because of the many different types of childhood cancer, treatment, prognosis, and other illness-related factors may vary considerably. Due to the variability in treatment and issues involved in different cancer diagnoses, research conducted with

such a heterogeneous group makes it difficult to draw firm conclusions. However, due to limited sample size, most of the literature discussing psychosocial variables for children and families affected by cancer does not differentiate between the effects of different types of cancer, but rather groups all cancers together to discuss their effects, similar to the “noncategorical” approach defined by Garstein et al. (1999) and recommended by Wallander and Varni (1998). In order to reduce variability, and based on recommendations noted previously by Garstein et al. (1999) and Pless and Perrin (1985), this paper will examine the research and literature on a somewhat more homogeneous group: children diagnosed with leukemia or lymphoblastic lymphoma. While this group may still vary somewhat in terms of prognosis and treatment, children with these diagnoses are more likely to be similar to each other than they are to children with another type of cancer. By studying these children and families, we can attempt to determine whether there are within-group differences in terms of the impact of this type of illness. This is therefore defined as a “mixed model” approach (Garstein et al., 1999; Pless & Perrin, 1985). Findings from previous research analyzing the differences in family experience and stress for families of children with AML as compared to those with ALL supported the joint analysis of both groups, as differences between them were nonsignificant (McGrath, Paton, & Huff, 2005).

Leukemia is the most common form of cancer in children, accounting for almost one third of all cancers in children under the age of 15 and one fourth of cancers occurring before age 20 (ACS, 2007; Armstrong & Mulhern, 1999). Approximately 3,800 children from birth to age 19 will develop leukemia in 2007 (ACS, 2007). It is a

cancer of the early blood-forming cells. It starts in the bone marrow, and spreads to the blood and other parts of the body (ACS, 2007). There are four main types of leukemia that are classified according to whether they are chronic or acute; most are acute (ACS, 2007). The most common types include two acute and two chronic: acute lymphocytic leukemia (ALL), acute myelogenous leukemia (AML), chronic lymphocytic leukemia (CLL), and chronic myelogenous leukemia (CML). ALL is the most common of these types; it accounts for about 73 percent of all childhood leukemias (ACS, 2007).

ALL is most commonly diagnosed in young children, with diagnoses peaking in children aged two to three years. AML is usually diagnosed within the first two years of life and is much less common in older children. However, diagnosis of AML increases again during the teenage years, and is the most common leukemia in adulthood (ACS, 2007). ALL is slightly more common among Caucasian children than African American and Asian American children, and is more common in boys than girls (ACS, 2007).

AML occurs equally as frequently across gender and ethnic groups. Due to advances in treatment, the five-year survival rate for children with ALL has steadily increased over time, and is currently about 87%; the rate is 53% for children with AML (ACS, 2007; Armstrong & Mulhern, 1999). Some of the signs and symptoms of leukemia may include fatigue, paleness of the skin, infection, easy bleeding or bruising, bone pain, swelling of the abdomen, swollen lymph nodes, enlargement of the thymus gland, headache, seizures, vomiting, rashes, gum problems, and/or weakness (ACS, 2007). A combination of lab tests (e.g., blood smear, bone marrow aspiration and biopsy, spinal tap, lymph node biopsy) and imaging scans (e.g., ultrasound, computed topography (CT)

scan, magnetic resonance imaging (MRI) scan, gallium scan, bone scan) is usually used to diagnose the illness (ACS, 2007).

Lymphoblastic lymphoma accounts for about 30% of lymphomas in children (ACS, 2007). The median age for children at diagnosis is about 9 years, which means that half the children are younger than 9 and the other half older than 9. It is most common in teenagers, and boys are affected twice as often as girls. Most cases of lymphoblastic lymphoma develop from a mass in the area behind the breast bone, which can interfere with breathing; difficulty with breathing may be the first symptom. Less often, lymphoblastic lymphoma may develop in the tonsils, lymph nodes of the neck, or other lymph nodes. It can spread very quickly to the bone marrow, other lymph nodes, the surface of the brain, and/or the membranes that surround the lungs and heart (ACS, 2007). The malignant cells of this lymphoma are the same as those in ALL in children. Thus, if more than 25% of the bone marrow is involved, the disease is reclassified as leukemia and treated as leukemia. As a result, treatment for lymphoblastic lymphoma is quite similar to that of ALL (ACS, 2007).

Pediatric oncologists typically refer to *staging* as a method for classifying cancers in terms of their progression; this allows them to estimate prognosis (ACS, 2007). Leukemia is not staged like other forms of cancer because it starts in the bone marrow and blood, whereas other types typically start in a distinct location and spread to the bone marrow and blood. For leukemia, progression of disease is determined by the collection of cancer cells in other organs, such as the liver, spleen, lymph nodes,

testicles, or central nervous system (ACS, 2007). Children with ALL and AML are divided into low-risk, standard-risk, and high-risk categories (ACS, 2007).

Children with leukemia and lymphoma are usually treated with chemotherapy protocols. Another possible treatment option is bone marrow or peripheral blood stem cell transplantation; this is usually reserved for children who are at high-risk for a poor prognosis (ACS, 2007). Specifically, chemotherapy treatment is divided into three phases for children with ALL: induction, consolidation (or intensification), and maintenance, and two phases for children with AML: induction and intensification. The induction phase typically lasts about one month, and requires frequent hospital visits to bring the child to an initial remission. At this point, the intensification phase begins in order to attack any “hiding” cancer cells. This phase typically lasts two to eight months depending on the child’s needs and the status of his/her illness. Once the cancer cells are under control, the child begins the maintenance phase of chemotherapy, which lasts for about two to three years (ACS, 2007; Armstrong & Mulhern, 1999). During chemotherapy, several other medications are often used to manage the symptoms related to treatment, including medicines that assist with nausea and pain. Some of these medications are associated with psychological side effects, including corticosteroids, or cognitive late effects, including methotrexate (Armstrong & Mulhern, 1999).

Psychosocial Adjustment in Children with Cancer/Leukemia

Theoretical Considerations

Family systems and social-ecological theories are the driving forces behind much of the research examining adjustment to childhood cancer (Kazak & Christakis, 1996).

The basic tenets of systems theory date back to the 1960's, and include the concepts that systems are composed of interrelated parts, that change in one part is associated with change in the others, that systems maintain a regular state of balance (i.e., homeostasis), and that systems maintain a balance of periods of change and stability (Kazak, 1989). Consideration of pediatric cancer patients within the context of their families and social systems has led to a level of awareness of the broad spectrum of concerns that the families face on a daily basis, much of which is only indirectly related to the child's cancer (e.g., transportation concerns, housing concerns, financial and job concerns, separation from friends, family, and school; Kazak & Christakis, 1996). A child's diagnosis is not contained within the child, but rather has ramifications for those in the child's system (Kazak, 1989).

Research examining the impact of stressors on family systems has been conducted in fields outside of psychology as well, including sociology and family therapy. The ABCX model of family reaction to stressful life events was developed in the 1960's by Hill (as cited in Kazak, 1989). This model identifies a stressful event (A) that interacts with family resources (B), family members' interpretation of the event (C), and an outcome (X). This model is helpful in thinking about chronic illness because it allows consideration for the changes that families may encounter over time. The same family may interpret initial diagnosis differently than ongoing treatment during the second year of illness (Kazak, 1989).

Another helpful model to consider is the Circumplex Model of Marital and Family Systems by Olson (1986). This model includes two dimensions: adaptability

(flexibility and ability to change) and cohesion (degree of emotional separateness or connection in a family). In general, moderate levels of each dimension are associated with better family functioning. Research examining these factors with regard to chronic illness has shown that these dimensions are related to individual family members' adjustment (Horwitz & Kazak, 1990).

One criticism of the family systems and social-ecological models is that they sometimes lose the importance of the impact of individual characteristics or factors. Thus, it is important to consider developmental psychology as well (Kazak, 1989). Bronfenbrenner's (1979) model is helpful in addressing these concerns because it links multiple systems together to show the ripple effect from a child's cancer diagnosis, starting from the individual child. Bronfenbrenner (1979) defined "social-ecology" as the study of the relation between the developing human being and the settings and contexts in which the person is actively involved: microsystem, mesosystem, exosystem, and macrosystem. Thus, the ill child may be considered at the center of a model of concentric rings with each circle representing an increasingly broad environment with which the child interacts (e.g., the child's family and close friends, the child's community and school, parents' social networks, the health care system; Kazak, 1992a). In addition, Bronfenbrenner (1979) expanded these notions to include the child's "chronosystem," which includes the concept of changes over time and periods of transition. More recently, examination of these levels has been referred to as the biopsychosocial approach (Kazak, 1992a).

It is also helpful to consider theory when discussing concepts of stress and change (Kazak, 1992b). Kazak (1992b) argues that change is inherently associated with some level of stress, but the level of stress is dependent on several factors, including: 1) the negative or positive nature of the change, 2) whether the change is anticipated or unexpected, 3) how “big” the change is, 4) whether the change is developmentally-expected or non-normative, and 5) whether or not the change is voluntary (i.e., sense of control). Thompson and Gustafson’s (1999) transitional stress and coping model is formulated within an ecological systems theory perspective, and has demonstrated utility in examining processes that contribute to the adjustment of children with chronic disorders and their mothers. Within this model, the illness is viewed as a stressor to which the child attempts to adapt. This adjustment is impacted by psychosocial (e.g., self-esteem, locus of control, coping behaviors, maternal adjustment), biomedical, and developmental processes. This model has been tested primarily with sickle cell and cystic fibrosis populations. Kusch, Labouvie, Ladisch, Fleischhack, and Bode’s (2000) Model of Coping with Diseases and Treatment (MCDT) also considers stressors due to the cancer disease and demands of the treatment, as well as stressors unrelated to the disease (family factors of risk and protection) in examining children’s coping. Primary family factors included social support, self-confidence, social competence, coherence of the family, socio-economic factors, and psychiatric disorders. Kusch et al. (2000) also defined coping in terms of both internal (cognitive-emotional coping) and external (health behavior) strategies.

Several theoretical constructs and models considering these many factors have been developed over the last ten to fifteen years in order to assist in the call for theory-driven research. In examining family stress, the Family Adjustment and Adaptation Response (FAAR) Model emphasizes the active processes that families engage in to balance “family demands” with “family capabilities” as these interact with “family meanings” to arrive at a level of “family adjustment” or “adaptation” (Patterson, 2002). The noted “demands” may be typical or atypical stressors, which may be discrete or chronic; Patterson (2002) noted that these demands may be thought of as “risk factors.” Then, the family’s “capabilities” are defined as tangible or psychosocial resources and coping behaviors (i.e., what the family has and what the family does). These can be thought of as “protective factors.” Once identified, these risk and protective factors are then examined by family members for meaning. Three levels of meaning to family members are possible: situational meanings, meaning for the identity of the family, or meaning for the family’s worldview. On a daily basis, families encounter this process with typical stressors, but there are times when an atypical stressor, or “crisis,” emerges, which can lead to significant changes in the family’s patterns and functioning (Patterson, 2002). In this model, the imbalance between demands and capabilities precipitates a crisis for a person or family, which could initiate or accelerate a downward trajectory in family functioning (Patterson, 2002). In McCubbin and McCubbin’s (1996) Resiliency Model of Family Stress Adjustment and Adaptation, having a child with cancer is viewed as a crisis situation for the family, prompting major changes for adaptation to occur.

In order to merge theory regarding ecological/systems theories and positive psychology, Sheridan, Warnes, Cowan, Schemm, and Clarke (2004) created a model of Family-Centered Positive Psychology (FCPP). This model is based on a definition of positive psychology, which identifies itself as the "...study of ordinary human strengths and virtues" with "...a more open and appreciative perspective regarding human potentials, motives, and capacities" (Sheridan et al., 2004, p. 7). The FCPP framework itself is defined as "...promot[ing] strengths and capacity-building within individuals and systems, rather than...focusing on the resolution of problems or remediation of deficiencies" (p. 7). This focus on strengths and protective factors is important for research and practice in pediatric psychology.

Finally, a driving theoretical framework for the present study is Wallander and Varni's (1992) integrative, multivariate Disability-Stress-Coping Model of adjustment. (See Figure A-1 for conceptual model.) This model is intended to be applicable to a variety of pediatric chronic physical disorders. Within the model, the physical illness is conceptualized as an ongoing chronic stressor for both children and their parents. Wallander and Varni (1998) defined chronic stressors as "persistent objective conditions that require continual readjustment, repeatedly interfering with the adequate performance of ordinary role-related activities" (p. 31). A major tenet of the model is that "modifiable risk and resistance factors can be identified empirically, which may provide heuristic guidance for the development of interventions for children and adolescents with chronic disorders" (p. 31). Risk factors include disease/disability parameters (e.g., diagnosis, handicap severity, medical complications, bowel/bladder

control, visibility, cognitive functioning, brain impairment), functional dependence in the activities of daily living, and psychosocial stressors (e.g., disability –related problems, major life events, daily hassles; Wallander & Varni, 1998).

In addition to the identified risk factors, there are also defined “resistance factors,” including intrapersonal factors (e.g., temperament, competence, effectance motivation, problem solving ability), social-ecological factors (e.g., family environment, social support, family members’ adaptation, utilitarian resources), and stress processing (e.g., cognitive appraisal, coping strategies). The interaction between these factors results in a picture of “adaptation,” which may include mental health, social functioning, and physical health (Wallander & Varni, 1992). Given the complexity of this theoretical model, the approach of most research testing the model has been to examine components or detailed submodels. There has been significant support for this model in the literature (Barakat & Kazak, 1999).

For the purposes of the present study, only a portion of the factors from Wallander et al.’s (2003) revised model will be examined as it is quite inclusive. (See Figure A-2 for conceptual model.) Thus, the factors will be limited to three main areas: illness-related factors (to include Wallander et al.’s condition parameters, and functional independence), within-child factors (to include Wallander et al.’s intrapersonal factors), and family context factors (to include Wallander et al.’s psychosocial stress and social-ecological factors). Wallander et al.’s stress processing factor will not be examined.

Previous Research Findings

Historically, having a child with a chronic illness, disabling condition, or potentially terminal disease has been recognized for the stressful effects that it can have on the child and family (Kazak, 1989). A diagnosis of pediatric cancer is just one example of such a stressor. Early psychological intervention in families facing childhood cancer often occurred with parents and other family members, rather than with the child, as many children were expected not to survive (Kazak, 1989; Kupst, 1992; Patenaude & Kupst, 2005). Early studies were often based on retrospective accounts, anecdotal information, or observations during a single occasion (Kupst, 1992). It was often assumed that the diagnosis of pediatric cancer itself led to individual and family dysfunction, and that family members required intensive psychological intervention (Kupst, 1992). Due to this increased survival rate, the role of mental health providers has shifted over time from preparing children and families for the child's death to the examination of psychosocial adjustment over the course of illness/treatment and subsequent long-term survival. Through research in these areas, we have learned that children and families coping with cancer will experience some or all of the psychosocial issues stated previously; many areas of daily functioning may be affected.

A major topic in the early literature of psychological adjustment and cancer in children was whether the child should be told the diagnosis (Van Dongen-Melman & Sanders-Woudstra, 1986). It was believed that children, especially young children, did not have a fear of death unless told. It was also assumed that children were not concerned about the illness, and that by shielding the child from the knowledge of the

illness, they were protected from anxiety (Van Dongen-Melman & Sanders-Woudstra, 1986). It also reflected the more paternalistic health care system of the time, which was not “customer-oriented.” Studies during the 1960’s indicated that keeping this information from children actually increased anxiety and depression as children created their own unrealistic fantasies about their situation.

As mortality rates for many cancers have decreased, increased interest in issues related to psychosocial adjustment to illness and coping with chronic illness has emerged in the field of pediatric psychology. While improvements in cancer treatment have lead to a significant increase in the number of children who survive cancer, these improvements have at the same time transformed cancer from an acute disease resulting in death into a chronic illness with both short- and long-term difficulties for children and their families (e.g., chemotherapy and related nausea and hair loss, painful procedures, neuropsychological sequelae, anxiety regarding potential relapse; Kazak & Christakis, 1996; Kupst, 1992). Despite this, many researchers in the mid- to late-1970’s observed that patients and families did not often develop serious problems, but adjusted fairly well to the experienced stressors (Kupst, 1992). These findings are similar to research examining children and families coping with other types of chronic illness as described previously.

In contrast, Varni and Katz (1987) reported that, “surprisingly few data-based studies appear in the literature on the psychological adjustment of children and adolescents with cancer” (p. 94). They reported that the available quantitative data revealed a vast majority of children that experienced at least mild difficulties in

adjustment (Varni & Katz, 1987). The behavioral problems and emotional disturbance often reported included anxiety, fear, depression, extreme dependency on parents, sleep disturbance, regression, anger, and withdrawal (Van Dongen-Melman & Sanders-Woudstra, 1986). Over time, research methodology has improved, clarifying the inconsistencies across early studies. Findings from longitudinal studies indicated that most children demonstrate improvements in adjustment and functioning over time (Varni & Katz, 1987). In fact, Stuber and Kazak (1999) reported that only a small subset of pediatric cancer patients tend to have serious psychological difficulties.

More recent studies have consistently shown a small but significant group of children and family members (about 25-30%) who do not cope well or who have significant personal, familial, and social difficulties (Patenaude & Kupst, 2005). In addition, distress in one area may occur despite generally good functioning in other areas (Patenaude & Kupst, 2005). There are findings regarding the types of adjustment difficulties that are most common in the minority of children who present with them including anxiety, problems with academic functioning, body and self-image, perceived stress, and attributional style (Apter, Farbstein, & Yaniv, 2003; Van Dongen-Melman & Sanders-Woudstra, 1986). Previous experiences, age and developmental level, current coping skills, and perceived control have been shown to be related to children's distress (Patenaude & Kupst, 2005). In a study highlighted by Wallander and Varni (1998), "negative affectivity" predicted perceived stress as well as the opposite. Thus, it may be that these factors are interactional, and may have implications for rates of depression and difficulties with self-esteem.

However, research examining rates of depression among children with cancer has been equivocal, with some studies reporting low levels of depression (Kazak & Christakis, 1996), and others finding the opposite (Chao, Chen, Wang, Wu, & Yeh, 2003). Children may experience an internal turmoil that can put them at increased risk for serious mental health problems. Research looking at how a diagnosis of cancer affects the diagnosed child has found that there are two main areas of functioning that are often affected: social adjustment with peers and emotional well-being (Vannatta & Gerhardt, 2003). These areas may be impacted because of the changes to the child's development of identity and self-concept (Vannatta & Gerhardt, 2003). Parental ratings regarding the effects of treatment on their children included observed concerns of: social isolation, excitability, tendency to brood, concentration problems, aggression, and sleep disturbances (Koch, Harter, Jakob, & Siegrist, 1996). These symptoms may be related to depression.

Examination of anxiety in children with cancer has been largely limited to procedural and anticipatory anxiety (i.e., related to painful procedures or anticipated reaction to procedures/medicine; Kazak & Nachman, 1991). Several studies have indicated that while procedural and anticipatory anxieties are frequent concerns, generalized anxiety is not especially prevalent (Kazak & Christakis, 1996). However, more recent research has examined post-traumatic stress as a potential outcome of childhood cancer diagnosis and treatment. Adjustment difficulties can be manifested in the form of post-traumatic stress symptoms (Vannatta & Gerhardt, 2003), including severe anxiety. In fact, diagnostic criteria for Posttraumatic Stress Disorder (PTSD)

include life-threatening illnesses, such as cancer, as precipitating traumatic events (Smith, Redd, Peyser, & Vogl, 1999). Several articles have been published recently regarding the association between cancer diagnosis and treatment and development of PTSD or related symptoms.

A literature review of PTSD and cancer indicated that while the *Diagnostic and Statistical Manual –IV – Text Revision* (DSM-IV-TR; American Psychological Association, 2000) specifically denoted “diagnosis with a life-threatening illness” as a traumatic experience within the scope of diagnostic criteria for PTSD, there remains controversy surrounding cancer’s inclusion as a stressor of this type (Phipps, Larson, Long, & Rai, 2006; Smith et al., 1999). In fact, the previous edition of the DSM specifically listed chronic illness as an exclusionary criteria in diagnosing PTSD (Stuber & Kazak, 1999). This may be because cancer differs from other known PTSD stressors as not a discrete event, but a series of events. In addition, the immediacy and degree of life-threat can vary considerably depending on the type of cancer, stage at diagnosis, and family history of illness (Smith et al., 1999). Despite these differences, however, subjective responses to diagnosis and treatment typically include feelings of fear, horror, and helplessness, and the intensity of these feelings may fluctuate over time (Smith et al., 1999; Stuber, 1995).

The association between cancer and PTSD has been examined more directly as research has increased regarding after-treatment/survivorship issues (Barakat, Kazak, Meadows, Casey, Meeske, & Stuber, 1997; Kazak, 2001; Kazak, Barakat, Meeske, Christakis, Meadows, Penati, et al., 1997). While the majority of childhood cancer

survivors do well psychologically after treatment ends, there is a subset of children who demonstrate symptoms reflective of the traumatic nature of cancer diagnosis and treatment (e.g., helplessness, horror, physiological arousal, reminders, intrusive thoughts; Kazak, 2001). Predominant studies have found rates of PTSD or posttraumatic symptoms in 1.6% (Kazak, 1997) to 21% (Stuber, Nader, Yasuda, & Pynoos, 1991) of childhood survivors. These findings have indicated several factors that seem to increase the chances that PTSD concerns will arise in certain children, including age, female gender, family and social support, history of previous trauma, the child's level of anxiety, experience of painful or traumatic experiences during the treatment process, and his/her subjective appraisal of the threat of the illness (Apter et al., 2003; Smith et al., 1999; Stuber & Kazak, 1999). Several reports have demonstrated that survivors of childhood cancer demonstrate fewer PTSD symptoms than survivors of other stressful events (e.g., natural disasters, major accidents, serious physical injury; Phipps et al., 2006).

Research examining psychological adjustment in adults with cancer indicates that approximately 10 to 25 percent of adult patients with cancer experience major depression (Levin & Kissane, 2006). Anxiety disorders are seen in 15-28 percent of adult patients with cancer (Levin & Kissane, 2006); however, findings with children and adolescents are not quite as clear. This reiterates the importance of developmental considerations in children's adjustment to cancer. There are likely particular adjustment trajectories that are specific to children at different developmental stages. Specifically, Quin (2004) found that adolescents may have more difficulty adjusting and coping with

the demands of treatment than younger children, leading to greater psychological difficulties. Other studies have found that adolescents can demonstrate more difficulties with adjustment due to physical impairments, changes in physical appearance, and/or conflict with their parents (Manne & Miller, 1998; Wallander & Varni, 1992). This may be because a cancer diagnosis can intensify the challenge of development during adolescence (Stuber & Kazak, 1999).

Adolescents interviewed about their experiences with cancer diagnosis and treatment provided information to assist in understanding areas that are most commonly difficult (Lockhart & Berard, 2001). They expressed feelings of emotional destabilization and shock at the time of diagnosis. They also indicated feelings of isolation and boredom during hospitalizations, as well as concerns that peers were withdrawing from them. At the same time, they wished for more privacy and independence. Adolescents expressed difficulties communicating with medical personnel, wishing that they had more information and control over their own treatment. In addition, they expressed concerns about the physical discomfort associated with their treatment (Lockhart & Berard, 2001).

Cancer treatment is different from other chronic illnesses and other traumatic events in that it occurs in phases: initial diagnosis and shock, treatment (including hospitalizations, procedures, chemotherapy), and completion of treatment (with feelings of uncertainty and anxiety of relapse; Kazak & Christakis, 1996). Even with this basic outline, the course of pediatric cancer treatment is often riddled with unknowns and unexpected outcomes. Because of this, research has begun to examine child and family

adaptation with regard to the course of adjustment over time; again, the range of adaptation to the illness is broad (Kazak & Christakis, 1996).

While research has demonstrated that the time of diagnosis is most stressful for parents, for children, the shock of diagnosis often serves a “protective” function of sorts, and it is only at 6- to 9-months post-diagnosis that children may begin to demonstrate more difficulties as they attempt to return to typical activities (Wallander & Varni, 1998). Given the nature of cancer treatment, the factor of time has been identified as significant in examining the nature and patterns of stress and adjustment for families. While some studies have indicated heightened stress at time of diagnosis, decreasing over time, others have found no significant decrease (Steele, Dreyer, & Phipps, 2004). There is a need to differentiate predictors of more and less positive adaptation.

In order to conceptualize differences among the stressors experienced by children and families, Kazak and Christakis (1996) categorized them as “initial stressors” (associated with diagnosis and early treatment) and “later stressors” (specific to certain treatments or particular outcomes of a disease or treatment). Koch et al. (1996) identified specific stressors for children during cancer treatment as: a high weekly time load, long periods of inpatient treatment, frequent relapses and grave complications, a high rate of absence from school and/or the repetition of school years. Initial stress is usually associated with a sense of loss of control, tremendous faith and hope in the medical team, increased guilt, and rapid family reorganization and gathering of information (Kazak & Christakis, 1996). Children are most likely to experience anxiety and pain during the initial stress period, especially related to procedures and nausea.

Later stressors may be associated with “serious acute episodes” due to infections, adverse reactions to treatment, bone marrow transplantation, or relapse. There has been some suggestion that cancers in childhood exert “cumulative” effects on children and their families in direct proportion to the length of illness and incapacitation (Garrison & McQuiston, 1989). Thus, shorter-term psychological consequences may not be as evident, and children may not necessarily habituate to the stressors of cancer with coping over time (Patenaude & Kupst, 2005).

Most investigations of the psychological impact of cancer diagnosis and treatment on pediatric survivors have found that the majority of survivors are functioning well (Stuber & Kazak, 1999). During treatment, several areas of psychosocial adjustment have been shown to be relatively resilient in the face of cancer diagnosis and treatment, including social development (Apter et al., 2003). Stuber & Kazak (1999) attribute this to the atypical experiences that children with cancer have, which may contribute to social/emotional maturity.

Per parental opinion, children were able to develop trusting relationships with medical personnel, had good understanding of their illnesses, and were active participants in their treatment (Koch et al., 1996). In a study comparing children with cancer to same-age classmates, Noll, Garstein, Vannatta, Correll, Bukowski, and Davies (1999) determined that children with cancer were perceived by teachers as being more sociable and by peers as being more socially accepted. Measures of depression, anxiety, loneliness, and self-concept showed no significant differences. There were no significant differences between parents’ ratings of psychosocial adjustment across child

groups. Noll et al. reported that these findings do not support disability/stress models of childhood chronic illness, and suggest considerable psychological hardiness.

In Lockhart and Berard's (2001) study of adolescents, findings indicated that patients expressed resilience in the face of their struggle, including an appreciation for medical personnel who showed empathy and understanding for their situation. They demonstrated appropriate self-management skills in regulation of their treatment adherence and social activities. Adolescents who were able to negotiate well with their parents were able to develop increased intimacy through mutual respect and emotional independence. Others were able to overcome concerns related to peer relationships in order to establish social supports (Lockhart & Berard, 2001). Stuber and Kazak (1999) and Wallander and Varni (1992) identified the presence of social support as a protective factor for adolescents undergoing treatment for cancer and other chronic illnesses.

While it is reassuring that most children with cancer do well psychologically, it is clearly an extremely difficult experience to go through, and must have important psychological implications (Kazak, 1993). In our current "era of positive psychology," Phipps (2005) suggested that there is an enigma to explain: How do children who are facing a life-threatening illness with multiple related stressors cope extraordinarily well? A recent trend in coping research involves less orientation toward classification of strategies and more interest in finding correlates or predictors of adaptation and adjustment (Kazak, 1993; Patenaude & Kupst, 2005). Previous research has documented that the usefulness of coping strategies depends on the characteristics of individuals, including existing coping resources, the characteristics of the situation,

specific demands, and time (Patenaude & Kupst, 2005). Research has demonstrated a need to identify factors that promote adjustment, as well as those that place children and families at risk (Horwitz & Kazak, 1990).

Recent reviews of the literature have identified factors that seem to impact adjustment, and are delineated between those associated with better adjustment and those associated with poorer adjustment (Patenaude & Kupst, 2005). Factors associated with better adjustment include: longer time since diagnosis, both younger and older age at diagnosis, previous adjustment and positive functioning, lower degree of perceived stress, higher cognitive functioning, higher family adaptability/cohesiveness, more family/social support, higher family coping/adjustment, and higher socioeconomic resources. Factors associated with poorer adjustment include the inverse of factors previously stated, as well as more severe physical sequelae/functional impairment. In particular, children who experience insults to their central nervous system (CNS) are at particular risk, including children with brain tumors or who receive intrathecal chemotherapy (Patenaude & Kupst, 2005). In addition, children who undergo treatment with unpredictable outcomes experience heightened distress.

In an examination of the psychosocial needs for individuals coping with cancer, Soothill, Francis, Awwad, Morris, Thomas, and McIlmurray (2004) found that needs may vary in both quantity and quality. Their findings indicate that those with greater needs generally express quantitative concerns or difficulties. In other words, those with the greatest needs tend to have needs “across the board,” whereas other individuals may only require assistance in a few areas. In addition to the *difficulties* that a subset of the

pediatric oncology population demonstrate, there are also *positive outcomes* that have been noted during and after treatment, including positively perceived changes in focus, a reordering of life priorities, an increased resilience, and a greater appreciation of life and relationships (Patenaude & Kupst, 2005). This makes examination of resiliency difficult as it may be both an “outcome” of cancer diagnosis and treatment, as well as a predictor of adjustment.

Patenaude and Kupst (2005) reported on the current state of the literature, as well as directions for future research. They described the current status of research in psycho-oncology as “...at the end of the beginning [in terms of] our understanding of psychosocial aspects of childhood cancer” (p. 19). Many studies have found that while the vast majority of children and families do cope and adjust to cancer diagnosis and treatment over time, there is a segment of this population that requires additional support (Quin, 2004). The current goal is to identify who might benefit from which intervention when. This information would help address the goal of establishing a national standard of care that takes into account physical, neurocognitive, and psychosocial functioning (Patenaude & Kupst, 2005).

Impact of Illness-Related Factors on Psychosocial Adjustment

There are several illness-related factors that are expected to impact children’s adjustment to chronic illness. In addition to illness-related factors that are specific to cancer (e.g., type of cancer, physical symptoms experienced, staging (level of risk), treatment type/phase), there are several factors related to the diagnosis, prognosis, and treatment of leukemia/lymphoblastic lymphoma that may impact the psychosocial

adjustment of children dealing with this illness. This may include the severity of the child's illness, his/her physical functionality, and the duration of illness and treatment. In addition, the child's sense of identity and self-concept may be altered due to his/her sense of mortality, his/her altered appearance (e.g., loss of hair, use of prosthetic limbs due to amputation, bloating or puffiness due to steroid use, weight loss or gain), frequent hospitalizations causing him/her to miss "normal" children's activities, forced changes in diet, and possible changes in the child's abilities due to treatment (e.g., cognitive impairments, fatigue, loss of emotional well-being, sterility, increased susceptibility to life-threatening infections and bleeding, hearing or visual problems; Armstrong & Briery, 2004; Bearison, 1991; Janes-Hodder & Keene, 2002; Kellerman, 1980; Vannatta & Gerhardt, 2003). Any or all of these factors may influence the severity of the impact of the illness or treatment on a given child and family. Specifically, this study will examine the severity of the child's illness and his/her physical functionality.

Physical Functionality

The physical symptoms that are part of day-to-day life for children with chronic illness can be stressors in and of themselves. In addition, the treatment required, or the illness itself, may cause changes to the child's appearance and/or his/her ability to participate in typical activities (Drotar & Bush, 1985). The impact and degree of these changes may vary significantly from child to child. Research examining the effect of physical illness and disability on psychosocial adjustment has largely been inconsistent (Kazak & Christakis, 1996). Previous reviews of the literature have generally indicated that despite physical limitations and their impact on children's quality of life, children

with cancer do not tend to report concerns that these limitations impact their overall emotional adjustment (Apter et al., 2003).

In contrast, some studies have demonstrated an association, particularly when it comes to issues of chronic pain associated with the illness and treatment. These problems often lead to internalizing concerns (e.g., depression and anxiety; Apter et al., 2003). Physical functioning and chronic pain can be associated with depressive symptoms, which in turn impact the length of hospital stays, higher disease morbidity, and dysfunctional behaviors (Apter et al., 2003). While previous research has not identified a direct link between illness severity/physical limitations and psychological stress, this relationship does not appear as clear as it sounds. The level of “physical incapacitation” appears to play a role (Garrison & McQuiston, 1989), as does the perception of illness severity or physical limitation. Noll et al. (1999) discovered that children with cancer were more concerned with their physical abilities than peers.

Results of a study involving adolescents with cancer determined that more physical impairment was significantly correlated with increased psychological distress (Manne & Miller, 1998). In fact, when examining the separate impacts of physical impairment, social support, and interpersonal conflict on psychological distress, physical impairment emerged as the factor accounting for the largest proportion of variance (Manne & Miller, 1998). Particularly distressing for these patients were issues of physical pain and interference in daily activity. Soothill et al. (2004) also found that “global health status” was significantly associated with psychosocial need.

On the other hand, Wallander and Varni (1992) reported that they have generally not found a relationship between medical parameters, disability status, or functional ability and behavioral adjustment in investigations of children with cancer. Rather, it appeared that social functioning and changes in appearance served as mediating factors between physical functioning and behavioral adjustment, particularly for adolescents (Wallander & Varni, 1998). At the same time, Wallander and Varni (1998) differentiated functional independence from these other factors, and indicated that it has been inversely associated with emotional distress and somatic symptoms.

Severity of Illness

In addition to issues related to physical functionality and pain, children with cancer also face issues related to the severity of their illness. It should be noted that much of the research examining the relationship between severity of illness and degree of psychological difficulties has not focused on children who are facing a life-threatening situation (Kazak & Christakis, 1996). Depending on children's staging classification, where they are in their treatment (i.e., induction, intensification, maintenance), and relapse status (i.e., one relapse, two relapses), their chances of long-term survival will differ. Despite improvements in cancer treatment, prognosis for many types of cancer remains guarded (Vannatta & Gerhardt, 2003).

For some children with cancer, the "seriousness" of their illness can include relapse and death. Janes-Hodder and Keene (2002) and Ekert (1989) argued that the subsequent return of cancer in children previously diagnosed (i.e., relapse) can sometimes be as traumatic to the child and family as the initial diagnosis. Ekert (1989)

stated that this is true for at least two reasons. First, because the family must come to terms with the fact that the initial treatment was not successful despite all the resources, as well as the emotional and physical pain that went into it. Second, because relapse generally indicates a poorer prognosis, it forces the family to consider what might happen if the child does not survive. Janes-Hodder and Keene (2002) described the feelings that parents have at the time of relapse as "...oscillat[ing] between optimism and panic" (p. 441). They stated that families wonder how they can expect the sick child to go through the pain of treatment again, and how they themselves will get through it. These authors also described relapse as a time for thoughtful consideration and decision-making regarding the probabilities of a cure, tumor control, and the impact of the disease and treatment options on the child's emotional and physical well-being (Janes-Hodder & Keene, 2002).

Gerhardt et al. (2004) indicated that illness characteristics (e.g., severity, type) often interact with individual and family variables to influence child adjustment rather than having a direct effect. Illness severity appears to account for a small portion of the variance in adjustment (up to 10%; Barakat & Kazak, 1999). The child and family's *perception* of the impact of the illness may be the most important influence on overall adjustment (Barakat & Kazak, 1999; Drotar & Bush, 1985).

Impact of Family Context Factors on Psychosocial Adjustment

For children, parents and other family members play a key role in the development and utilization of coping strategies in the face of crisis or trauma. Because of this, children's adjustment and coping cannot be examined outside of the family

system's context. Kazak, Rourke, and Crump (2003b) highlighted the importance of family systems in pediatric psychology research and practice, and encouraged pediatric psychologists to incorporate broader perspectives in their work. They argued that future research should ask questions that take perspectives from multiple informants in the child's life, and should view these responses as interactional. Some familial factors that may impact children with cancer include: maternal adjustment, marital and family adjustment or conflict, family support or cohesiveness, parent ratings of life stressors, family functioning, family psychological resources, and parental stress. The child's adjustment to diagnosis and treatment may be affected by his/her overall sense of how well his/her family is adjusted or conversely, distressed. Family members can both provide support and coping resources for children, or they can interfere with the coping process (Compas et al., 1992).

Kazak (1997) illustrated several "facts" about families, including that child and parent adjustment are interrelated. Previous reviews of the literature have also emphasized the importance of the impact of family-context factors on children's emotional adjustment to cancer diagnosis and treatment (Compas et al., 1992; Wallander & Varni, 1992). Family support in pediatric populations has a direct relationship with child adjustment (Compas et al., 1992). In fact, Barakat and Kazak (1999) report that parent/family factors (e.g., parent adjustment, family functioning, family stress) are stronger predictors of child adjustment than disease/disability characteristics (e.g., severity, prognosis, functional status). However, the family influence can be difficult to measure as it is defined through *patterns* of interaction (Barakat & Kazak, 1999).

Barakat and Kazak (1999) indicated that family functioning changes over the course of a chronic illness and influences child adjustment concurrently and prospectively, making research in this area difficult. Per Wallander and Varni's (1998) model, family functioning has been shown to be a significant predictor of adjustment at 6 and 9 months after diagnosis, suggesting that it may be more important over the course of illness than at the time of diagnosis. Again, this highlights the importance of studying these factors over time as the effect of chronic illness is not static (Wallander & Varni, 1998). Overall, previous research indicates that examining both parenting stress and family functioning simultaneously would likely yield a more complete understanding of family system functioning within pediatric populations (Streisand, Kazak, & Tercyak, 2003). This is particularly true for families currently on treatment.

Parenting Stress

Early literature examining the impact of childhood cancer on families focused on the impact on parents at the time of diagnosis. Because children did not commonly survive their illness, parents were forced to cope with the likelihood of their child's death upon diagnosis (Van Dongen-Melman & Sanders-Woudstra, 1986). Interestingly, however, even with improvements in cancer treatment and survival, many parents continue to respond similarly to their child's diagnosis, and the most intense levels of parental distress continue to be commonly seen at this time. This distress generally improves over the course of the next six years (Kupst & Schulman, 1988).

Findings have indicated that parents often have greater adjustment difficulties than their children, demonstrating clinically significant depressive and anxious

symptoms (Apter et al., 2003; Vannatta & Gerhardt, 2003). Specifically, mothers of children with cancer have been found to demonstrate greater depressive symptomatology than mothers of children with acute illnesses (Barrera, D'Agostino, Gibson, Gilbert, Weksberg, & Malkin, 2004). Both parents will likely need to attend to the sick child more often, and more family resources have to go toward the child and his/her treatment (Vannatta & Gerhardt, 2003). This parental distress related to caregiving for a chronically ill child has been shown to be associated with a significantly higher incidence of psychosomatic and physical complaints (Koch et al., 1996), as well as poorer family functioning outcomes (Streisand et al., 2003).

Just as recent research has examined the impact of PTSD symptoms on children diagnosed with cancer, so have published articles documented similar phenomena in parents of diagnosed children (Barakat et al., 1997; Kazak, 2001; Kazak et al., 1997). In fact, findings have actually demonstrated more consistently high rates of PTSD among parents of children with cancer than the children themselves (Phipps et al., 2006). Predominant studies have reported rates of PTSD symptomatology from 10.2% (Kazak, 1997) to 39% (Stuber, Christakis, Houskamp, & Kazak, 1996) in mothers, and 9.8% (Kazak, 1997) to 33.3% (Stuber, Christakis, Houskamp & Kazak, 1996) in fathers. More recent research has demonstrated posttraumatic stress symptoms (PTSS) rates of about 30% in mothers, with 13.7% meeting full criteria for PTSD (Kazak, Alderfer, Rourke, Simms, Streisand, & Grossman, 2004). In fact, 99% of this sample included at least one family member demonstrating re-experiencing symptoms (Kazak et al., 2004). Findings by Best, Streisand, Catania, and Kazak (2001) indicated that PTSS in parents

after treatment can be predicted by parental anxiety and distress during treatment. An additional point of note is that levels of parental PTSS have been associated with increased incidence of PTSD in their children (Phipps et al., 2006).

Wijnberg-Williams, Kamps, Klip, and Hoekstra-Weebers (2006) investigated the psychological functioning of parents of children with cancer over a five-year period, and found that while stress decreased over time, a significant number of parents still suffer from clinical distress after five years. Similarly, Kazak and Barakat (1997) found strong patterns of association between parenting stress during treatment and later parental adjustment for both mothers and fathers. Social support did not appear to assist in mother's adjustment, as is commonly found (Wijnberg-Williams et al., 2006). Parents with relapsed children, as well as those with high levels of psychosomatic complaints at diagnosis, are at higher risk for long-term difficulties.

Four distinct patterns of maternal distress were identified by Steele et al. (2004): high, moderate, declining, and low. The presence of distinct groups among mothers of children with cancer assists in explaining some of the variance observed in the literature regarding family distress over the course of treatment. Rather than a single pattern of heightened distress at certain time points (e.g., diagnosis), it is likely that many patterns of stress and coping exist. Thus, not all mothers are at risk for development of psychological difficulties. Upon examination of the impact of these patterns on child distress, Steele et al. determined that high maternal distress was associated with higher child emotional distress than the "declining" or "low" groups. While these findings were based on mother-report of child distress, it was noted that even mothers in the

declining and low groups reported high emotional distress for their children (Steele et al., 2004).

Lindahl-Norberg, Lindblad, and Boman (2005) examined the use of coping strategies among parents of children with cancer in comparison to parents of children with no serious or chronic diseases. Findings indicated that both groups of parents utilized similar coping strategies, and that this also did not vary over the course of the child's illness or by type of cancer. Wallander and Varni (1998) reported that cognitive appraisal of stressful events is often more important than the event itself in determining whether it will lead to psychosocial stress. In mothers of children with cancer, emotion-focused coping and child behavior were shown to be predictive of depression, anxiety, and global mental health (Barrera et al., 2004). However, parental reactions to childhood cancer are influenced by many variables, including personality, and previous experience with illness and caretaking (Kazak & Nachman, 1991). Parental guilt at the time of the child's diagnosis may impact the development of psychopathology as well; feelings of guilt are demonstrated to be associated with parental attributions of the cause of the illness (Chao et al., 2003). If parents believed that the illness was due to environmental factors that reflect on their level of care for the children (e.g., diet, exposure to toxins), they were more likely to express guilt. In examination of how use of coping strategies served a protective function against anxiety and depression, use of active problem-solving was more helpful in comparison to avoidance and passivity (Lindahl-Norberg et al., 2005).

While there is evidence in the literature that parents experience increased levels of depressive symptoms and other indicators of psychological distress, it is unclear how these symptoms may impact their child's coping (Compas et al., 1992). Kupst (1992) reported that children's coping is significantly related to the adequacy of their parents' coping. Positive coping tends to "run in families" when examined prospectively (Kupst & Schulman, 1988). From the perspective of social learning theory, parents are models for coping and influence children's own coping behaviors through observation and learning processes (Compas et al., 1992). Children often look to their parents to determine how to judge a situation (Stuber, 1995). Children may mirror the anxiety of other family members, leading to generalized anxiety problems (Kazak & Nachman, 1991). Gutkin and Conoley's (1990) paradox of treatment in child psychology seems important here in that the treatment of children often requires treatment of the adults in their environments. If findings are indicative that parents' own adjustment impacts child adjustment, then our treatment efforts should, in theory be focused on parents so as to indirectly impact children.

Additional evidence for the interactional nature of these variables is found in the literature examining parents' *relationship* with their ill child. Results of a study by Chao et al. (2003) found that after a child's cancer diagnosis, parents identified feeling more protective, more lenient, and less demanding of their sick child. In a study of adolescent adjustment, adolescents indicated that they noticed significantly more conflict with their mothers and fathers during treatment (Manne & Miller, 1998). Another factor that impacts the relationship between parents and children during cancer treatment is

communication style. Cline, Harper, Penner, Peterson, Taub, and Albrecht (2006) examined how parents communicated with their children during painful procedures, such as lumbar punctures. Findings indicated that when children received invalidating messages, they demonstrated significantly higher levels of distress. Specifically, processes such as commitment, help, support, and the open expression of feelings assist children in their adjustment (Wallander & Varni, 1998).

While some families demonstrate clinically significant difficulties with anxiety or depression, other families demonstrate tremendous resilience in the face of these changes and are able to develop new family practices and values in order to cope and adjust (Gerhardt et al., 2004). Additionally, certain families are able to utilize the child's cancer diagnosis to develop a new awareness of life and a change in life priorities (Koch et al., 1996). In fact, only a small subgroup of mothers demonstrate severe emotional distress (Gerhardt et al., 2004). Previous research has demonstrated that these differences are often mediated by the levels of cohesion and expressiveness in families (Apter et al., 2003; Wallander & Varni, 1998). This has also been found to be the case when based on adolescent report: adolescents with cancer reported perceived family cohesion and adaptability as strongly related to their post-treatment psychological adjustment (Rait, Ostroff, Smith, Cella, Tan, & Lesko, 1992). These family "resources" appear to serve a protective factor for chronically ill children. However, the nature of such resources is unclear (Wallander & Varni, 1992).

The interaction between parent and child adjustment appears to be bidirectional. That is to say, family adjustment has also been shown to be related to individual child

adjustment. Parents respond to their children's behavior as well as their own thoughts and interpretations. If the child is demonstrating emotional or behavioral difficulties, it is more difficult for the family to maintain adjustment (Gerhardt et al., 2004). Similarly, Kazak and Barakat (1997) found that parental perceptions of the child's overall adjustment behaviors are potent predictors of long-term family adjustment. One would expect, then, to view this interactional relationship as significant throughout the cancer experience (Stuber, 1995). In fact, Stuber (1995) reported previous findings that when a stepwise multiple regression was performed, mother's symptoms were the only significant contributor to the child's appraisal of treatment intensity, accounting for 35% of the variance. These findings were interpreted to mean that mother's own anxiety affected her appraisal of diagnosis and treatment, which affected children's appraisal, and subsequently both the child and mother's symptomatology (Stuber, 1995).

Studies have tended to focus on the impact on and functioning of mothers, and less is known about how the cancer experience impacts fathers. In general, previous research has demonstrated that there tend to be gender differences in coping styles between mothers and fathers; mothers tend to assume primary caretaking responsibility for the sick child, while fathers tend to care for siblings and assume primary breadwinning duties (Elliott Brown & Barbarin, 1996; Kazak & Nachman, 1991; Koch et al., 1996; Kolbrun-Svavarsdottir, 2005; McGrath et al., 2005; Quin, 2004). Because of these role differences, each parent may have distinct concerns related to their unique circumstances – mothers have increased social isolation and more interaction with the sick child and medical staff; fathers have stress related to meeting obligations in home

and work settings and are isolated from hospital staff (Kazak & Nachman, 1991). As a result, mothers and fathers appear to respond differently to the emotional demands of treatment, and mothers are at greater risk for development of posttraumatic symptoms (Best et al., 2001). Fathers appear to be at greater risk for distress if they experience dissatisfaction with social support and perceived negative interactions (Wijnberg-Williams et al., 2006).

Thompson and Gustafson (1999) provided a good overview of research regarding parental adjustment to chronic illness up until that date. Their conclusions offer suggestions regarding directions for future research. It is known that some children and families can cope and adjust with chronic illness, while others have more difficulty. Information regarding contributing factors to each of these pathways is lacking. In addition, studies have been largely based on self-report, both for parents and for children themselves, and it is important to include multiple reporters for more accurate information. In order to incorporate a developmental perspective, there is a need for more longitudinal research. More research should be theory driven. Intervention studies are needed to determine the best way to treat families. “Ultimately, our goals must be to measure family structure and function accurately and without oversimplifying rich and complex relationships” (Kazak, 1993, p. 317). Specifically, research integrating the emotional and behavioral distress related to cancer treatment and issues of family adaptation is important (Kazak, 1993). Finally, Kazak and Nachman (1991) and Wallander and Varni (1998) highlighted the importance of additional research in areas

related to family context differences among families that are ethnically and socioeconomically diverse.

Family Psychosocial Stressors

Often times, symptoms of parenting stress are related to the extreme changes that occur within the family after a child is diagnosed. Parents who are responsible for caring for a child with cancer often feel socially isolated, and social support has emerged as an important factor impacting overall family functioning (Kazak & Christakis, 1996; Vannatta & Gerhardt, 2003). Investigation by Manne, Duhamel, and Redd (2000) indicated that mothers were more likely to demonstrate posttraumatic stress when they perceived less belonging support and more social constraints.

In addition to the stress of caring for a child with cancer, many families also have to cope with concurrent stressors (e.g., complications of the child's cancer, death or illness in other loved-ones, occupational changes, financial problems, other changes within the family; Kazak & Christakis, 1996; Varni & Katz, 1987). Sources of parental stress include the time and financial burdens of cancer treatment (Koch et al., 1996). These findings indicate that families likely require assistance across a broad range of problems. In general, families who demonstrate good coping attribute this to social support, marital satisfaction, fewer concurrent stressors, and open communication (Kupst & Schulman, 1988).

Family's responses will largely be determined by their values, rules, and beliefs (Vannatta & Gerhardt, 2003). In addition, family response likely differs by both disease and treatment-related factors, as well as characteristics of the family prior to diagnosis.

Previous research indicates that families who are flexible, integrated into a social support network, able to balance the demands of the illness with other family needs and responsibilities, have positive attributions, demonstrate active coping, and encourage the development of individuals within the family will demonstrate better adjustment than those who do not have these characteristics (Kazak, Rourke, & Crump, 2003b).

Impact of Personal Resiliency on Psychosocial Adjustment

There also may be within-child factors that can impact psychosocial adjustment to cancer, including demographic characteristics, temperament, use of coping methods, self-concept, intelligence, age at diagnosis, social support, and cognitive processes (e.g., perceived stress, perception of physical appearance, and stigma). Research findings indicate that within-child factors (e.g., self-concept, temperament, coping) may be the strongest predictors of child adjustment (Barakat & Kazak, 1999). One such within-child factor is personal resiliency.

The definition of resiliency offered by Wyman, Sandler, Wolchik, and Nelson (2000) suggests that we can think of this concept as "...a child's achievement of positive developmental outcomes and avoidance of maladaptive outcomes, under significantly adverse conditions" (p. 133). "Resilience" is considered an emergent process in individuals, and not a stable trait (Patterson, 2002). Discussions in the literature examine how "significant" a risk factor must be in order for a good outcome to be evidence of resilience (Patterson, 2002). "Exposure to an unexpected traumatic event" has been described as evidence of significant risk, and the diagnosis of chronic illness in a child and the ongoing strains associated with managing it are considered "significant"

(Patterson, 2002, p. 239). This stressor can push families to the “extremes of functioning” (i.e., much worse or much stronger). Only those who emerge from significant risk competently and demonstrate greater than average strengths are considered “resilient.”

Resiliency is often conceptualized as falling under the broader concept that Lorion (2000) defines as “wellness.” Wellness is seen as something that represents a broad expanse of human functioning, distinct from psychopathology. These strength areas can provide children with the ability to continue their lives in an adaptive way even in the presence of hardship. Lorion (2000) describes research in wellness as a “...conceptual, methodological, and political new frontier for the mental health sciences [that] promises to challenge a significant portion of the major assumptions underlying existing work in our disciplines, to move us closer to our social, behavioral, and physical science colleagues and, especially, to bring us to issues of *health* rather than pathology” (p. 23).

Children with cancer have demonstrated incredible hardiness and resiliency in the face of their struggle. As introduced above, research examining children’s adjustment to chronic illness has demonstrated that children can demonstrate all three pathways of Gerhardt’s (2004) model: resilience, hardiness, and enhancement. Some have explained the findings of resilience research by indicating that cancer survivors and their parents use denial as a coping mechanism to minimize the effects of treatment on psychological functioning; this may be an adaptive mechanism, allowing families to continue with “normal” activities to the extent possible (Barakat & Kazak, 1999).

Children's resiliency has emerged as an important area of inquiry (Richardson, 2002) and the field of child psychology has encouraged research with a "positive psychology" orientation (Masten, 2001; Power, DuPaul, Shapiro, & Kazak, 2003). It is an important area of inquiry because while we know quite a bit about the processes that lead to maladjustment, we do not know much about what leads to adjustment. These protective factors are just as important as the problematic ones in informing our practice. The goal of current research is to approach families within a framework of resilience that leads to identification of competencies, resources, and risks in order to identify aspects of the illness and family functioning that may differentiate the families that do well from those who do not (Barakat & Kazak, 1999).

Impact of Relationships on Child Resiliency

The positive, "wellness," framework assumes that the development of healthy personal and environmental systems leads to positive well-being and resiliency (Wyman et al., 2000). This assumption is important when talking about children because of the many systems in children's lives (e.g., parent-child relationships, peer groups, classrooms). In other words, if children are able to develop and maintain healthy relationships with their parents and other family members, they will be more likely to demonstrate normative adjustment to life stressors, and thus be more resilient.

Intrapersonal Factors and Child Resiliency

The described hardiness or seemingly miraculous ability of children with cancer to adjust to their illness and treatment has often been attributed to personal characteristics within the child that were present before diagnosis (Phipps et al., 2006).

Desired characteristics may include low trait anxiety and general positive adaptive style (Phipps et al., 2006). Specifically, children with cancer have been rated by peers and teachers as having good social and leadership skills, are well-liked by peers, and have lower rates of substance use as adolescents in comparison to same-aged peers (Gerhardt et al., 2004). Wallander and Varni (1998) discuss the impact of child temperament on adjustment, defining temperament in terms of personality traits that are genetic in origin and appear during the first year of life. It has been demonstrated that temperament characteristics may predispose children to certain patterns of behavioral adjustment or maladjustment, as influenced by the interplay between temperament and environmental demands. In general, “greater emotionality” predicts poorer adjustment outcomes (Wallander & Varni, 1998).

Purpose of the Present Study

Because of the vast number of factors to consider, it is important to provide practitioners in this area with a working model of assessment to inform intervention. Previous research has largely been theoretical, or has examined only specific parts of the general model. In order to inform treatment, it is important to gather data in all of these areas within the same sample. In addition, there is a breadth of literature that finds that the impact of cancer on families is greater at the time of diagnosis than it is later in treatment (Ekert, 1989; Vannatta & Gerhardt, 2003). Vannatta and Gerhardt (2003) argued that children and families adjusting to a cancer diagnosis experience the psychosocial difficulties discussed above at the time of diagnosis, but following a period of adjustment, are not found to function differently from families without a sick child.

In other words, they stated that the adjustment problems associated with a cancer diagnosis are not long-lasting or pervasive, but are rather specific to the time of diagnosis when symptomatology and level of impairment is held constant. They stated that researchers have attributed this to a certain adaptive style that children with cancer have that makes them more “hardy” than controls. However, it seems unlikely that children who have this type of adaptive style would be more likely to be diagnosed with cancer, which is what this argument implies. It is possible that the children may mature over time and learn to cope with the diagnosis.

Vannatta and Gerhardt (2003) suggested that some children may be at increased risk for more long-term psychosocial problems depending on specific individual, diagnostic, or treatment factors. Some specific examples of these include: the location and type of tumor and the treatment consequences related to this, the current and late effects of treatment, age at diagnosis, time since diagnosis, and the dose and intensity of treatment (Armstrong & Briery, 2004). This information seems to indicate at least two things: 1) that children diagnosed with cancer and their families will all adjust differently to the new situation; and 2) that there are many treatment and outcome factors related to the disease of cancer that seem to predict adjustment variables that will fluctuate over time. For example, in addition to the adjustment involved in initial diagnosis and long-term changes and care, children and families dealing with cancer also must adjust to the possibilities of relapse and the death of the sick child.

While much of the research has focused on the distress and adjustment associated with these three distinct points in time: initial diagnosis of cancer in a child, diagnosis of

relapsed cancer, and the child's death, it is important to recognize the child and family's equally distressing adjustment to short-term and long-term changes (e.g., altered appearance, hospitalization, nutrition changes, educational changes, social changes, financial strain, emotional and behavioral concerns, treatment effects). There appears to be a reciprocal interaction between the ongoing illness-related, individual, and systemic changes and individual/familial adjustment.

In other words, **the diagnosis of childhood cancer creates a fluctuating process of adjustment to change over time rather than a distinct event.** Wallander et al.'s (2003) model fails to account for the factor of time, and this seems to be an important variable to consider in addition to the illness-related, family context, and within-child factors when examining childhood cancer processes.

Given the question presented here regarding the adjustment over the course of illness, it is important to emphasize the relationship in the literature between the effects of acute and chronic adverse conditions (Wyman et al., 2000). These authors viewed acute adverse events as often initiating chronic conditions. In the case of childhood cancer, we may think of the time period surrounding initial physical symptoms and diagnosis as an acute event, with chronic adverse conditions to follow. The chronic course of the illness may not in its entirety be considered "adverse" as a child may find relief from initial symptoms, and may find a new sense of "normal" while on the journey; however, there is a chronicity to the treatments used for cancer (i.e., chemotherapy, frequent follow-up appointments, extended hospitalizations). Wyman et al. (2000) also discussed the importance of the co-occurrence of adverse events, which

may be seen in families coping with cancer who deal not only with the chronic illness itself, but also financial stressors (e.g., medical bills, travel costs to hospitals far away from home, parents choosing to leave their place of employment to care-take), marital stressors (e.g., having to spend time apart if one parent is at the hospital with the sick child and the other stays home for work or child-care reasons, disagreements regarding medical decisions), or academic concerns (e.g., getting behind on work because of hospitalizations preventing school attendance, cognitive sequelae of treatment affecting performance).

In addition to examining each of these factors within one sample, and analyzing the factors cross-sectionally using the factors of relapse status and stage in treatment, there are multiple other gaps in the research that should be examined further to provide practitioners with a more accurate picture of these issues. In terms of family context factors, Kazak, Cant, Jensen, McSherry, Rourke, Hwang, et al. (2003a) stated that future research examining family-level variables in chronic childhood illness should also examine family cohesion/conflict, socio-economic status (SES), patterns of family interaction, parenting style, and parent-child relatedness as possible factors influencing adjustment. Several of these and other factors will be examined utilizing a measure that was developed by Kazak and colleagues, including family demographics (i.e., ethnicity, parental education level, number/age of persons in home, marital status), spirituality, availability of support systems, availability of resources (i.e., transportation, health insurance, finances), parental stressors, and parental beliefs about the child's illness.

In addition to family context factors, child resiliency is also seen to be an important potential factor impacting adjustment. However, there has been limited investigation of this concept as it relates to adjustment to cancer. Given the observation often provided in the literature regarding the hardness of children with cancer, research testing this hypothesis would be important. This is seen as an important paradigm shift away from a problem-oriented focus. In other words, we will examine the way in which children's strengths may allow them to adjust to the stressors of cancer treatment in a normative fashion. This is different from examining how the stressors may cause maladjustment. It answers the question, what are some children doing that is helpful in their adjustment; not, what are they doing that is not helpful? In most current research of children with cancer, emotional and behavioral strengths are simply inferred from the absence of maladjustment and clinical factors. Currently available assessment tools allow us to measure resiliency/wellness more directly by focusing on children's strengths. In this sense, a child's resiliency may be operationally defined as the presence of protective strengths in the areas of interpersonal relationships, sense of family belonging, self-confidence, sense of school success, and emotional skills.

Therefore, while we have some information on adjustment of children with cancer, many of the studies that have been done have had methodological concerns that limit findings. Carefully designed studies that identify the emergence and maintenance of outcomes could add critical information (Vannatta & Gerhardt, 2003). Study of cancer-related, family context, and child resiliency and adjustment factors in the course of chronic illness will assist us in conceptualizing childhood cancer as a context-

dependent process rather than a distinct event at diagnosis. Viewing coping and adjustment in this manner utilizing a data set from a single sample of children and families provides psychologists working with pediatric populations with information that will serve to inform psychosocial treatment.

Given the current state of the literature and the call for more research in family systems and child resiliency in pediatric psychology, the purpose of the present study is to examine the relationships between illness-related factors, family context, and child resiliency as guided by portions of Wallander et al.'s (2003) model. Specifically, this study will examine illness-related factors as predictors of child adjustment to cancer, family context factors as correlates of child adjustment to cancer, child resiliency as a predictor of child adjustment to cancer, and child adjustment to cancer as a process over the course of illness. The variables to be examined in the proposed study include:

1. Independent Variables:

- a. Illness-related factors:

- i. Severity of child's illness as rated by medical staff
 - ii. Child's health and physical functioning as rated by child's parent
 - iii. Child's health and physical functioning as rated by child

- b. Family Context:

- i. Family psychosocial risk as rated by child's parent
 - ii. Frequency of parental emotional distress as rated by child's parent
 - iii. Difficulty of parental emotional distress as rated by child's parent

- c. Child Resiliency

- i. Child's overall strengths as rated by child's parent
 - ii. Child's overall strengths as rated by child
- 2. Dependent Variables:
 - a. Child self-reported adjustment
 - b. Parent-reported child adjustment
- 3. Demographic Variables:
 - a. Age
 - b. Gender
 - c. Ethnicity
 - d. Age at diagnosis
 - e. Type of cancer
 - f. Staging risk
 - g. Type of current treatment
 - h. Location of treatment
- 4. Grouping variables to assess adjustment over course of illness:
 - a. Stage in treatment
 - b. Relapse status

Globally, the study will answer the following question: how do each of the independent variables relate to child adjustment to cancer? (See Figure 1 for conceptual model.) It is hypothesized that many of the factors will intercorrelate and interact, so it will be important to examine the relationships between these factors as well.

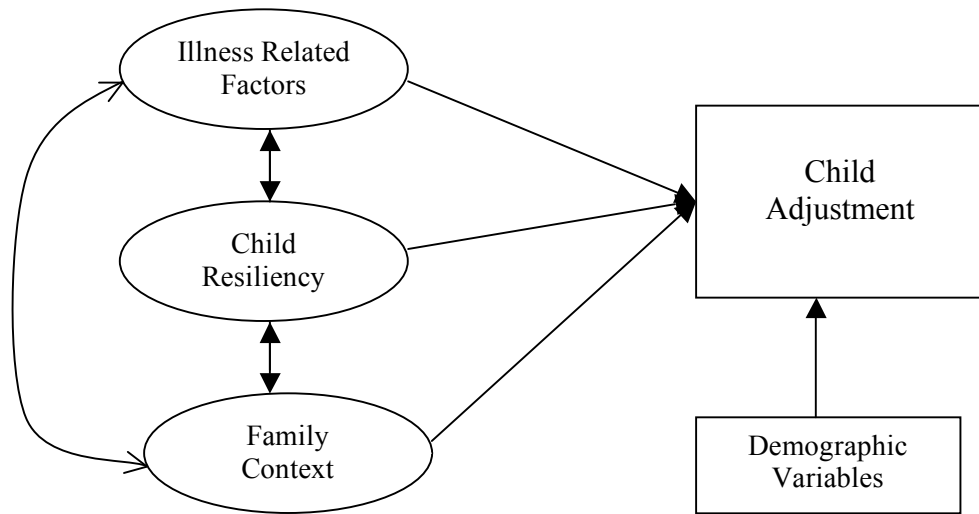


Figure 1. Conceptual model: Independent variables to child adjustment.

There are several specific research questions as follows:

Research Question 1:

To what extent are illness-related factors related to child adjustment? It is hypothesized that illness-related factors as measured in terms of Physical Health and Functioning as reported by parent and child on the Pediatric Quality of Life Inventory (PedsQL) General Module form, as well as overall Illness Severity as reported by medical personnel on the Severity of Illness Scale (SOIS), will be significantly and negatively correlated with Child Adjustment as reported by parent and child on

composite scores of the Behavior Assessment System for Children – 2nd Edition (BASC-2; i.e., as health problems increase, adjustment will decrease).

Research Question 2:

Does relapse status significantly affect child adjustment? It is hypothesized that those children who have experienced one or more relapses will evidence greater adjustment difficulties as reported by parent and child on composite scores of the BASC-2. These children may be classified into two groups: relapse/no relapse.

Research Question 3:

Does the stage of treatment affect child adjustment? It is hypothesized that those children who are in the induction or intensification phases of treatment will evidence greater adjustment difficulties as reported by parent and child on the composite scores of the BASC-2. These children will be classified into two groups: induction/intensification or maintenance.

Research Question 4:

To what extent is family context related to child adjustment? It is hypothesized that the Frequency and Difficulty of Parental Emotional Distress as measured by parent report on the Pediatric Inventory for Parents (PIP) will correlate with the child's adjustment as measured by parent and child report on the composite scores of the BASC-2. It is also hypothesized that the Overall Psychosocial Stress of the family as reported by parent on the Psychosocial Assessment Tool – 2nd Edition (PAT 2.0) will correlate with Child Adjustment as reported by parent and child on the composite scores of the BASC-2.

Research Question 5:

To what extent is child resiliency related to child adjustment? It is hypothesized that those children who demonstrate greater overall strengths as measured by parent and child report on the Behavioral and Emotional Rating Scale—Second Edition (BERS-2) will also demonstrate better overall adjustment as measured by parent and child report on the composite scores of the BASC-2.

Research Question 6:

To what extent does parental distress moderate the relationship between parent report of child adjustment and child report of child adjustment? It is hypothesized that the frequency and difficulty of parenting stress as measured by the Pediatric Inventory for Parents (PIP) will serve as a moderator between parental report of child adjustment (BASC-2) and child report of self-adjustment (BASC-2).

Potential Implications of Study

This analysis is unique in that it uses a systems perspective and focuses on children's resiliency. In other words, the analysis looks at system-level factors that can predict children's emotional/behavioral distress/problems as well as psychosocial adjustment/functioning. The answers to the questions listed above will help to conceptualize some of the factors involved in the psychosocial adjustment to childhood cancer. It is important to understand the relationships between illness-related, family context, and child resiliency factors in order to inform psychosocial treatment with pediatric populations. If pediatric psychologists have a good understanding of these factors, they will be in a better position to work collaboratively with behavioral medicine

teams to ensure that each family's needs are met in such a way that the best possible adjustment and functioning of children with cancer can be predicted. In other words, it will provide direction to the field that will inform practice.

CHAPTER III

METHODS

Participants

Participants included 37 children and adolescents diagnosed with cancer. Of these, 18 (48.6%) were female and 19 (51.4%) were male. The mean age was 12.49 (Range=6 to 18; SD=4.17) and the ethnic composition of the sample was 40.5% Caucasian, 32.4% Hispanic/Latino, 18.9% African American, 5.4% Native American, and 2.7% Middle Eastern. There were 7 Spanish-speaking families (18.9%), and the remainder completed questionnaires in English (81.1%). One caregiver of each of these children was asked to participate in the study. In the majority of cases (78.4%), the child's mother served as the caregiver participant. Additional caregivers included fathers (18.9%) and grandmothers (2.7%). One medical provider of each of the participating children was also asked to participate. In most cases (59.5%), the child's nurse practitioner served as the medical staff member participant. Additional participants included physicians (37.8%) and physician's assistants (2.7%).

Examination of factors related to the child's illness revealed that a vast majority of participants (89.2%) had been diagnosed with Acute Lymphoblastic Leukemia (ALL). Participants with Acute Myelogenous Leukemia (AML) made up 5.4% of the sample, as did participants with lymphoma. Most participants (32.4%) were considered "high-risk" in terms of staging characteristics, while 18.9% were classified as "standard-risk," and 5.4% were "low-risk." Due to the use of an incorrect demographic form at one site, data on risk are missing for 16 participants (43.2%). The average age at diagnosis for the

sample was 10.4 (SD=5.15; Range = 2 to 18); participants had been in treatment for an average of 25.31 months (SD=26.9; Range = 1.5 to 127 months).

A majority of participants were receiving treatment at the University of Texas M. D. Anderson Cancer Center (UTMDACC) in Houston, Texas (75.7%), while the remaining participants were receiving care at the University of Minnesota Medical Center-Fairview (UMMC-F; 24.3%). The sample was fairly evenly split across treatment status groups, with 48.6% in induction or intensification/consolidation phases and 51.4% in maintenance phase. Most participants were receiving “standard” forms of treatment (51.4%), while 5.4% were receiving “experimental” treatments. Typically, standard treatments are those that have been identified in the field as the most appropriate, given our current state of knowledge about what is effective for a certain type of cancer at a particular age. New treatments or combinations of treatments are tested against the current standard in experimental trials. When this is done, then a child is entered on a protocol and randomized either to the standard or the new treatment (i.e., Phase III protocol). The new treatment is usually the standard treatment with certain parts missing or added (e.g., reduced radiation dose, different type of chemotherapy). Another type of experimental treatment is sometimes offered when children are at the end of life. These are sometimes referred to as Phase I - II treatment protocols, which test the limits of a drug that holds some amount of promise for the child’s particular disease. Due to the use of an incorrect demographic form at one site, data on type of treatment are missing for 16 participants (43.2%). A majority of participants (73%) had

never experienced a relapse of their disease, while 27% had relapsed. (See Table I for demographics).

Children were eligible to participate in this study if they: a) were between the ages of 6 and 18 years, b) had been diagnosed with any form of leukemia or lymphoblastic lymphoma, c) were currently on treatment, d) were able to speak and read English or Spanish well-enough to complete questionnaires with some assistance from researchers, and e) had at least one caregiver who was able to speak and read English or Spanish well-enough to complete questionnaires. Children were ineligible if they were currently in a medical crisis (e.g., in ICU, receiving hospice care) as determined by their medical care provider. Data were collected over a year-long period (2006-2007) at the above listed sites in Texas and Minnesota. Each child and caregiver who participated received a \$10 voucher for hospital parking, as well as a selection of \$1-3 “prize” (e.g., gel pens, stickers, pencil bags, sparkle powder).

Table I. Demographic Characteristics of Participants

	Frequencies	%
<i>Gender</i>		
Males	18	48.6
Females	19	51.4
<i>Ethnicity</i>		
White/Caucasian	15	40.5
Hispanic/Latino	12	32.4
Black/African-American	7	18.9
Native American	2	5.4
Middle Eastern	1	2.7
<i>Language</i>		
English	30	81.1

Table I. Continued

	Frequencies	%
<i>Language (Continued)</i>		
Spanish	7	18.9
<i>Age</i>		
Six	1	2.7
Seven	7	18.9
Eight	1	2.7
Nine	3	8.1
Ten	2	5.4
Eleven	0	0.0
Twelve	4	10.8
Thirteen	4	10.8
Fourteen	1	2.7
Fifteen	2	5.4
Sixteen	2	5.4
Seventeen	4	10.8
Eighteen	6	16.2
<i>Site</i>		
UTMDACC	28	75.7
UMMC-F	9	24.3
<i>Caregiver Participant</i>		
Mother	29	78.4
Father	7	18.9
Grandmother	1	2.7
<i>Medical Provider Participant</i>		
Nurse Practitioner	22	59.5
Physician	14	37.8
Physician's Assistant	1	2.7
<i>Type of Cancer</i>		
ALL	33	89.2
AML	2	5.4
Lymphoma	2	5.4
<i>Staging</i>		
High-Risk	12	32.4
Standard-Risk	7	18.9
Low-Risk	2	5.4
Missing	16	43.2
<i>Stage in Treatment</i>		
Induction/Intensification	18	48.6
Maintenance	19	51.4

Table I. Continued

	Frequencies	%
<i>Type of Treatment</i>		
Standard	19	51.4
Experimental	2	5.4
Missing	16	43.2
<i>Relapse Status</i>		
Presence of Relapse	10	27.0
No Relapse	27	73.0

Measures

While the general theoretical constructs important in analysis of children's adjustment to chronic illness are commonly agreed upon, there has been great variability and difficulty in identifying assessment measures to evaluate these constructs. This is especially true for analysis of family-based variables and illness-related variables (Kazak, 1989). Instruments used to measure maladjustment and family context issues have largely been normed with homogenous groups of children and families, creating difficulties in drawing conclusions with diverse families (Kazak & Nachman, 1991). In addition, commonly utilized questionnaires for measuring emotional and behavioral problems in children and adolescents may not be appropriate for use with pediatric populations as symptoms associated with depression and anxiety can often be related to the child's illness or treatment, resulting in false positive identification (e.g., fatigue, somatic symptoms, weight loss, decreased appetite; Apter et al., 2003). Additionally,

the presence of “somatic complaints” in children with chronic illness has an entirely different meaning from this symptom in the general population (Kupst, 1999).

It is often considered “best practice” in research to utilize a neutral, comparison group in order to ensure that your findings are different than what would be expected in the general population. There are difficulties in doing this for research regarding chronic illness, for many of the questionnaires that are used are not appropriate across chronically-ill and non-ill groups. Alternatively, more general measures may inappropriately measure aspects that have little to do with psychopathology and are related to chronic illness (e.g., somatization).

Despite this, children’s adjustment to chronic illness is usually measured using general behavioral rating scales or quality of life rating scales in the absence of more appropriate measures. Previous research has documented the impact of response shift on the validity of outcome data in this population (Brossart, Clay, & Willson, 2002). “Response shift” was defined in this article as “...the change in one’s internal standard,” or the basis on which individuals determine their own level of functioning on a particular dimension (p. 98). This problem has been noted to be particularly evident in data collected from cancer patients in that they appear to underreport psychological or emotional symptoms (Brossart et al., 2002). This shift appears to occur as a result of their illness; that is, the significant life event of being diagnosed with cancer leads to a change in the social comparisons that one makes (Brossart et al., 2002). This characteristic of respondents may assist in understanding why there has been a weak link between physical functioning/illness severity and psychological adjustment.

Previous research has also documented that caregivers who are distressed are more likely to perceive their children as having adjustment problems. Parental distress is a major determinant of a parent's assessment of child functioning and behavior (Phipps et al., 2006). Research in the area of pediatric chronic illness has commonly demonstrated that children often deny emotional and behavioral concerns on questionnaires, while their parents often report observed concerns for their children (Chao et al., 2003).

Because of these concerns, it is important to assess children's adjustment using both self- and caregiver-report measures. A complete assessment of child adjustment should include data from more than one informant whenever possible (Varni, Blount, & Quiggins, 1998). No one informant should be considered more accurate than another; rather, they should be viewed as different perceptions based on interpretation (Varni et al., 1998). This "multi-source method" (i.e., caregiver and child report) assists in ensuring the most accurate reporting possible (Brossart et al., 2002). Examination of caregiver-child agreement in ratings of health-related quality of life (HRQOL) have been inconclusive, with some studies finding correlations between raters and others finding that caregivers generally report more concerns than children and adolescents. However, it should be noted that children with cancer and their caregivers have been shown to demonstrate greater interrater reliability than the general population.

These measurement issues were carefully considered in the selection of instruments to measure the constructs of the present study. All utilized measures have

demonstrated hardiness in the literature with regard to use with pediatric populations, and specifically with pediatric oncology populations.

Demographic Information

Demographic and clinical information was provided by medical staff members (e.g., research assistants) through review of medical records and/or consultation with medical providers. The Demographic Form (See Appendix 4.) included the following variables for data collection regarding child participants: age, ethnicity, gender, grade, diagnosis date, type of leukemia, staging, relapse status, stage in treatment, time since diagnosis, age at diagnosis, and type of current treatment. Due to a miscommunication between the Principal Investigator and research staff, 16 participants received an incorrect demographic form at the UTMDACC site. Once this problem was identified, it was corrected.

Independent Variables

Illness-related factors: severity of illness. Pediatric oncologists and nurse practitioners usually work as a team in the treatment of children with cancer. Because of their expertise and frequent contact with the children, they are in a good position to estimate the severity of each child's illness. This is based not only on medical data, but also on their expert observation of each child and their abilities and limitations due to the illness. Staging factors mentioned previously may influence a physician's/nurse practitioner's opinion regarding the severity of the child's illness, including: the type of leukemia, the child's age, or the presence of relapse.

In order to measure the severity of the child's illness, a physician or nurse practitioner completed the Severity of Illness Scale (SOIS; Young-Saleme & Prevatt, 2001). This measure is a short, six-item questionnaire that focuses on the medical severity of illness of children with cancer from the point of view of medical personnel. Medical staff responded on 7-point scales that are question-specific. Each question provides a quantitative rating on one factor related to illness severity: 1) degree of physical impairment, 2) likelihood of improvement/worsening of physical impairment over time, 3) frequency of medical procedures, 4) likelihood of increase/decrease of frequency of medical procedures over time, 5) frequency of hospitalization, and 6) frequency of child's participation in age-appropriate activities. Raw scores were entered for responses on each individual item, as well as a total score comprised of the sum of each individual response.

Analysis of this scale in previous research indicated appropriate test-retest reliability (.96 after two weeks and .92 after three months), interrater reliability (.89 between physicians and nurses), criterion-related validity (ability to discriminate both bone marrow transplant and relapse status), and test utility (according to positive ratings for brevity, ease of completion, and usefulness in depicting medical severity of disease; Young-Saleme & Prevatt, 2001).

Illness-related factors: physical functionality. One subscale of the Pediatric Quality of Life Inventory (PedsQL™; Varni, 1998) was used as a measure of child-reported and caregiver-reported physical health and functioning. The PedsQL™ measures health-related quality of life (HRQOL) in healthy children and adolescents, as

well as those with acute and chronic health conditions. The PedsQL™ has a 23-item Generic Core Scales form for both caregiver-report (ages 2-18) and child-report (ages 5-18). Different forms are utilized depending on the age of the child (i.e., Young Child form for ages 5-7, Child form for ages 8-12, and Teen form for ages 13-18).

These scales provide measures of physical (8 items), emotional (5 items), social (5 items), and school (5 items) functioning from both the caregiver and child's perspectives. Each form asks the same questions, but re-words them to reflect the different respondent's perspectives. Respondents provide information on a five-point scale regarding "how much of a problem" each of the items have been for the child during the previous month (0=never a problem to 4=almost always a problem). The Generic Core Scales provide four scale scores that correspond with each group of questions: Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning. It also provides three summary scores: Psychosocial Health Summary Score, Physical Health Summary Score, and Total Scale Score. For scoring purposes, items are reverse-scored and linearly transformed to a 0-100 scale, so that higher scores indicate better HRQOL. The Physical Functioning score is the only score used from this measure; participants did not complete the other scales of this measure.

Research examining the reliability and validity of the PedsQL™ has indicated that the general form demonstrates internal consistency reliability coefficients among pediatric oncology populations of 0.88 for the child-report and 0.93 for the parent report (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). Examination of internal consistency for the Physical Health Summary Score has yielded similar results

(alpha=0.80 on child-report, alpha=0.88 on parent report; Varni, Seid, & Kurtin, 2001). Validity was established on this scale through its ability to distinguish between children with and without cancer, as well as between children with cancer who are on- and off-treatment (Varni et al., 2001; Varni et al., 2002). Several studies have looked at the appropriateness of this scale for use with pediatric oncology populations with positive results (Eiser, Eiser, & Greco, 2004; Eiser, Greco, Vance, Horne, & Glaser, 2004; Eiser, Vance, Horne, Glaser, & Galvin, 2003).

Family context factors: family psychosocial stress/risk. Psychosocial information was gathered from each family using the Psychosocial Assessment Tool – Version 2.0 (PAT 2.0) developed by Kazak et al. (2004) regarding family-level factors that may impact overall familial stress (e.g, socioeconomic status, access to social support, children’s emotional/behavioral difficulties, environmental stressors, and cognitive belief systems held by the family that may impact their ability to cope). This 60-item scale was developed at the Children’s Hospital of Philadelphia (CHOP) to predict family functioning and need for psychological support. Questions relate to several domains: Family Structure, Family Resources, Social Support, Child Knowledge, School Attendance, Child Emotional and Behavioral Concerns, Child Maturity for Age, Marital and Family Problems, Family Beliefs, and Other Stressors. The measure yields an overall psychosocial risk score comprised of the domains. Each item is scored categorically as either “At Risk” or “No Risk,” depending on whether it meets the risk criteria outlined by Kazak et al. (2004). The scale has a maximum possible score of 18, if all items across all Risk Domains were endorsed. Analyses of this

measure's utility and measurement characteristics are currently being conducted by Kazak and her colleagues, and are not available in the current literature (Kazak et al., 2003a; Kazak, 2001). Examination of the first version of the PAT indicated promising results in terms of its ability to distinguish families at higher risk for development of psychosocial difficulties requiring intervention (Kazak, Prusak, McSherry, Simms, Beele, Rourke, et al., 2001). Preliminary analyses of the PAT 2.0 indicated that parent total PAT 2.0 scores ranged from 0 to 10.5, with a median score of 1.8, for mothers ($M = 2.2$ [$SD = 1.9$]); fathers scores ranged from 0 to 8.3, with a median of 1.5 ($M = 1.9$ [$SD = 1.5$]; Kazak et al., 2004). No normative data are available for this instrument using a sample of non-ill children.

Family context factors: parenting stress. Parental emotional distress will be measured using the Pediatric Inventory for Parents (PIP); Streisand, Braniecki, Tercyak, & Kazak, 2001). This measure is a 42-item caregiver self-report form examining stress associated with caring for a child with a chronic illness. The PIP was not available in Spanish; thus, only English-speaking participants were able to complete this form. Respondents answer on two separate five-point scales indicating both the frequency of these behaviors (1=never to 5=very often) as well as the level of difficulty experienced (1=not at all to 5=extremely). Instructions indicate that frequency should be answered with regard to the past seven days, and difficulty should be answered with regard to their general sense of things. The scale provides four index scores in the areas of: communication, medical care, role functioning, and emotional functioning. It is scored separately for each of these domains across two scales: Frequency (F) and Difficulty

(D). There is also a total score comprised of the sum for each of the four domains, yielding Total F and Total D scores. Items are scored as endorsed by respondents, ranging from one to five. The range of each of the Total F and Total D scores is 42 to 210. Higher scores indicate greater pediatric parenting stress (Streisand et al., 2003). Research demonstrating the reliability and validity of the scale indicated that internal consistency reliability coefficients ranged from .80 to .96, and construct validity was established through correlations with established measures of state anxiety and parenting stress (Streisand et al., 2001).

Child resiliency. Children's resiliency will be measured using the Behavioral and Emotional Rating Scale—Second Edition (BERS-2; Epstein, 2004). The BERS-2 provides a measure of personal strengths and competencies of children ages five to 18 years. The BERS-2 has a Youth Rating Scale (child self-report) and Parent Rating Scale. The BERS-2 was not available in Spanish; thus, only English-speaking participants were able to complete this form. Each form has 52 questions, and respondents answer on a four-point scale (from 0=not at all like you to 3=very much like you) to indicate how much each statement describes them (or their child) over the last three months. The scales measure five different strengths, including: Interpersonal Strength (15 items), Family Involvement (10 items), Intrapersonal Strength (11 items), School Functioning (9 items), and Affective Strength (7 items).

Each of the five strength categories generates a scale score, and there is also an overall index score, termed the BERS-2 Strength Index. The measure is scored using the answer form's format of copying responses into category columns, creating column

subtotals, and finally generating a Total Raw Score. This Raw Score is transferred to the front of the form, where a percentile rank score and scaled scores using gender-based norms are obtained using the BERS-2 Manual (Epstein, 2004). The sum of scaled scores is then used to determine the BERS-2 Strength Index score. Both the Parent Rating Scale and Youth Rating Scale are administered and scored in the same manner.

The psychometric properties of the original BERS measure are well-established with reliability coefficients from 0.79 to 0.99 (Epstein, Harniss, Robbins, Wheeler, Cyrulik, Kriz, et al., 2003; Epstein, Ryser, & Pearson, 2002; Trout, Ryan, LaVigne, & Epstein, 2003; Walrath, Mandell, Holden, & Santiago, 2004), but this second edition is in need of additional study. Further, there is demonstrated utility of the BERS with both community (Trout et al., 2003) and clinical populations (Walrath et al., 2004) in order to measure emotional and behavioral strengths. Epstein (2004) conducted analyses of the internal consistency reliability of the BERS-2 subtests, and determined that this could be established with both children without disabilities and with children who were emotionally disturbed. Coefficients exceeded .80 for each subtest and .95 for the overall score. According to the BERS-2 manual, over 15 studies have confirmed the BERS's content, construct, and criterion-related validity (Epstein, 2004). One example of these by Epstein, Mooney, Ryser, and Pierce (2004) established the convergent validity of the BERS-2: Youth Rating Scale with the Social Skills Rating Scale ($r=.71$) and Achenbach's Youth Self Report ($r=.40$). They also examined test-retest reliability, with coefficients ranging from .84 to .91 across testing sessions (Epstein et al., 2004).

Dependent Variables

Child psychosocial adjustment. For the purposes of this study, the Behavior Assessment System for Children—Second Edition (BASC-2; Reynolds & Kamphaus, 2004) will be used as the measure of overall child adjustment, including both caregiver- and child-report. The BASC-2 scale provides a measure of clinical and affective difficulties of children ages six to 21 years. The BASC-2 has a Self-Report of Personality (SRP) and Parent Rating Scale (PRS).

The PRS contains 150-160 items depending on the child's age and measures both adaptive and problem behaviors in both community and home settings. There are separate caregiver forms for ages 6 to 11 and ages 12 to 21. The scale uses a four-point response format indicating how each statement reflects the frequency of the child's behavior over the last several months (i.e., whether the behavior occurs never, sometimes, often, or almost always). The answers to these questions provide specific information regarding the following clinical and adaptive areas: Activities of Daily Living, Adaptability, Aggression, Anxiety, Attention Problems, Atypicality, Conduct Problems, Depression, Functional Communication, Hyperactivity, Leadership, Social Skills, Somatization, and Withdrawal.

The self-report form has 137-139 questions depending on the child's age, and responses are given in a mixed format, with both multiple choice (i.e., never, sometimes, often, or almost always) and true-false questions. The Self-Report scale also measures adaptive and problem behaviors in the following areas for both children (ages 8 to 11) and adolescents (ages 12 to 21): Anxiety, Attention Problems, Attitude to School,

Attitude to Teachers, Atypicality, Depression, Hyperactivity, Interpersonal Relations, Locus of Control, Relations with Parents, Self-Esteem, Self-Reliance, Sense of Inadequacy, and Social Stress. Adolescents also answer questions on the following scales: Sensation Seeking and Somatization.

In addition to the scores generated in the specific areas listed above, the BASC-2 also provides composite scores in the caregiver-reported areas of: Internalizing Problems, Externalizing Problems, Behavioral Symptoms Index, and Adaptive Skills. Composite scores on the BASC-2 self-report form include: School Problems, Internalizing Problems, Inattention/Hyperactivity, Emotional Symptoms Index, and Personal Adjustment. Each of these scores will be used in the analysis as overall measures of child adjustment. Low composite scores in clinical areas (i.e., internalizing, externalizing, behavioral/emotional symptoms, school problems, inattention/hyperactivity) indicate appropriate adjustment, while a high clinical scores indicates maladjustment. The opposite is true for adaptive/personal adjustment scores (i.e., higher scores indicate better adjustment). As T-scores, adjustment on clinical scales is considered to be within the average range if scores are between 40 and 60. Scores from 60 to 70 are considered “At Risk” and scores that are above 70 are considered “Clinically Significant.” Adjustment on adaptive scales is considered to be within the average range if scores are above 40. The “At Risk” range falls between 30 and 40, and the “Clinically Significant” range is below 30. These scores are gained using the BASC-2 ASSIST scoring software; both the Parent Rating Scale and Self-Report of Personality are administered and scored in the same manner.

The psychometric properties of the original BASC-2 measure are well-established, and the second edition is in need of additional study. Self-study by Reynolds and Kamphaus (2004) indicated acceptable levels of reliability and validity. However, there has not been documented research examining the utility of the BASC-2 with pediatric populations. It is expected that there may be concerns related to the appropriateness of the Somatization scale, for example. Each of the composite scores will be used in the analysis in order to consider a broad range of “adjustment.” Each of the areas assessed by the BASC-2 may be important in the lives of children with cancer. They often miss school, and may subsequently demonstrate school problems. Current research is indicative of difficulties with inattention or hyperactivity due to the effects of intrathecal chemotherapy. In addition, internalizing (e.g., depression, anxiety) and externalizing (e.g., anger, conduct problems) symptoms may be observed due to coping and adjustment difficulties related to the illness.

Procedure

Approval for conducting the present research was initially obtained through the Institutional Review Board (IRB) at UTMDACC on November 17, 2005. The study was then reviewed for approval by the IRB at Texas A&M University – College Station, and approval was granted on March 1, 2006. Additional IRB approval was also granted by UMMC-F on May 3, 2006, and the Texas A&M IRB approval was amended to reflect data collection at this additional site. The study has been granted continuing approval by Institutional Review Boards at all three institutions over the course of the study.

Patients and families were identified as eligible by medical staff members (e.g., research assistants, nurse data managers) at each participating institution. Once identified, each child's medical provider (e.g., nurse practitioner, physician) was contacted in order to schedule a time to approach the family based on their next appointment at the hospital for medical treatment. On the day of the child's appointment, his/her medical provider would obtain verbal permission from the family to allow the researchers to talk with them about the study. If the family agreed to talk with the researcher, a member of the research team (e.g., principal investigator, research assistant) would present information to the family regarding the study in order to determine whether they would like to participate in the study. If so, written consent was obtained from a caregiver and assent was obtained from the children. The participating caregiver also signed a HIPPA form indicating permission for the researcher to obtain protected health information as noted on the demographic form. Written consent to participate was then also obtained from the participating child's medical provider.

Each participating caregiver and child was assigned a unique identification number, and questionnaire packets for each participant was prepared with the appropriate identification number. Packets were given to each caregiver and child, which included five scales for a caregiver to complete (BASC-2-PRS, PAT 2.0, BERS-2 Parent Report, PIP, and PedsQL – General Module), and two or three scales (depending on age) for the child to complete (BASC-2-SRP, BERS-2 Youth Report, and PedsQL – General Module; See Table A-3). Researchers offered to provide reading assistance to young child participants. Both child and caregiver questionnaire packets varied based on

the age of the child; therefore, each participating family received age-appropriate forms. The child's medical provider was given one scale (SOIS), as well as the demographic form, to complete.

It was estimated that it would take approximately 45 minutes to one hour for caregivers/caregivers to complete their questionnaires, about 10 to 15 minutes for children ages 6 or 7, about 30 to 45 minutes for children ages 8 to 18, and about 3 to 5 minutes for medical providers. Given this time commitment, families were offered an opportunity for their child to select a \$1.00 to \$3.00 item out of an age-appropriate "treasure box," and caregivers were provided with a \$10.00 voucher to put towards parking or other expenses during their time at the hospital. If families were unable to complete the measures during their time at the hospital, they were given a stamped envelope to return the forms to the researcher at no cost. When families agreed to participate, but did not return the questionnaires by mail, follow-up phone calls were made in order to remind them to return the forms. Of the 50 families approached to participate, 43 agreed. One eligible family was not approached due to current medical crises. Of those who agreed to participate, 14 were contacted by phone with reminders to return questionnaires. Nine of these returned completed packets after the phone call reminder; five never returned their packets. One participant's packet was lost in the mail; all data regarding this participant were eliminated from the data set. One participant requested a new packet, indicating that he/she had lost the first one, and this second packet was returned. Two other participants returned incomplete or invalid questionnaires; these data were not included in the data set.

CHAPTER IV

RESULTS

Descriptive Statistics

The means, standard deviations, and other statistics of normality for independent variables (i.e., caregiver-report, child-report, and medical provider-report) were computed, and results are listed in Table II. PAT 2.0 scores range from 0 to 18 (higher scores indicate poorer family functioning). PIP scores range from 42 to 210 (higher scores indicate greater parenting stress). BERS-2 scores are presented as standard scores. SOIS scores range from 6 to 42 (higher scores indicate greater illness severity). PedsQL scores range from 0 to 100 (higher scores indicate better physical functioning). Table III presents the means, standard deviations, and other statistics of normality for all child outcome variables.

Table II. Descriptive Statistics for Measures of Independent Variables

Measure	N	Min	Max	Mean	SD	Skewness	SE	Kurtosis	SE
PAT 2.0 Risk Score	37	0.18	6.81	2.90	1.72	0.44	0.39	-0.16	0.76
PIP Frequency Score	30	47	180	116.43	33.91	-0.37	0.43	-0.38	0.83
PIP Difficulty Score	30	24	168	105.9	34.59	-0.49	0.43	-0.04	0.83
BERS Strength Index Parent Report	30	62	130	103.67	17.29	-0.33	0.43	-0.52	0.83
BERS Strength Index Youth Report	35	71	135	105.8	17.25	-0.36	0.4	-0.62	0.78

Table II. Continued

Measure	N	Min	Max	Mean	SD	Skewness	SE	Kurtosis	SE
SOIS Total	37	11	39	21.51	7.15	0.8	0.39	-0.26	0.76
PedsQL Physical Functioning, Parent Report	36	3.57	100	61.85	29.79	-0.15	0.39	-1.30	0.77
PedsQL Physical Functioning, Child Report	36	3.57	100	63.10	26.9	-0.48	0.39	-0.85	0.77

Note: PAT 2.0 = Psychosocial Assessment Tool; PIP = Pediatric Inventory for Parents; BERS = Behavioral and Emotional Rating Scale; SOIS = Severity of Illness Scale; PedsQL = Pediatric Quality of Life Inventory.

Table III. Descriptive Statistics for Measures of Dependent Variables

Measure	N	Min	Max	Mean	SD	Skewness	SE	Kurtosis	SE
BASC-2 Externalizing Parent Report	36	37	82	48.31	10.08	1.32	0.39	2.34	0.77
BASC-2 Internalizing Parent Report	36	34	81	55.31	11.26	0.26	0.39	-0.51	0.77
BASC-2 Behavioral Symptoms Index, Parent Report	36	37	69	49.39	8.72	0.44	0.39	-0.54	0.77
BASC-2 Adaptive Skills, Parent Report	36	32	68	50.19	9.06	0.06	0.39	-0.50	0.77
BASC-2 School Problems, Child Report	28	30	82	47.50	9.88	1.46	0.44	4.52	0.86

Table III. Continued

Measure	N	Min	Max	Mean	SD	Skewness	SE	Kurtosis	SE
BASC-2 Internalizing, Child Report	28	35	71	50.07	8.87	0.37	0.44	-0.36	0.86
BASC-2 Inattention/ Hyperactivity, Child Report	28	35	67	50.89	7.56	0.01	0.44	-0.33	0.86
BASC-2 Emotional Symptoms Index, Child Report	28	37	66	50.11	8.19	0.31	0.44	-0.91	0.86
BASC-2 Personal Adjustment, Child Report	28	32	62	50.64	8.79	-0.78	0.44	-0.54	0.86

Note: BASC-2 = Behavior Assessment Scale for Children – 2nd Edition; BASC-2 scores are presented as T scores (for most scales, higher scores indicate maladjustment; for the Adaptive Composite and Personal Adjustment scales, lower scores indicate maladjustment).

Mean scores on the BASC-2 (both caregiver and child report) were within the average range. These results suggest that children with leukemia or lymphoma do not differ in terms of overall emotional and behavioral adjustment from the BASC-2 normative sample. Analysis of the internal consistency of the BASC-2 scales with the current sample revealed variable reliability depending on the scales. All caregiver-report scales demonstrated high reliability, ranging from $\alpha = 0.80$ to 0.91 . Child self-report scales demonstrated less internal consistency, particularly on scales examining

Externalizing Behaviors ($\alpha = 0.49$ and 0.52) or Adaptive Behaviors ($\alpha = 0.61$). Scales of Internalizing Behaviors demonstrated appropriate reliability, however ($\alpha = 0.84$).

While a majority of participants demonstrated overall emotional and behavioral symptoms within the normative range, there were a subset of children, that reported difficulties, as evidenced by the following. Based on caregiver-reported Externalizing symptoms (i.e., Hyperactivity, Aggression, Conduct Problems), 5.5% of the sample fell within the “At Risk” range and 5.5% fell within the “Clinically Significant” range. Additionally, a smaller subset of children were in the “At Risk” range (3.6%) and the “Clinically Significant” range (3.6%) when the dependent variables were child-reported school problems (i.e., Attitude to School, Attitude to Teachers, Sensation Seeking). 10.7% were in the “At Risk” range for child-reported Inattention/Hyperactivity symptoms.

Caregiver-reported Internalizing symptoms (i.e., Anxiety, Depression, Somatization) revealed that 22.2% of the sample fell within the “At Risk” range and 11.1% fell within the “Clinically Significant” range. Children’s self-report ratings also indicated that 10.7% of the sample reported Internalizing symptoms (i.e., Social Stress, Anxiety, Depression, Sense of Inadequacy, Somatization) within the “At Risk” range, and 3.6% were within the “Clinically Significant” range.

Overall emotional and behavioral difficulties as rated by caregivers (i.e., Hyperactivity, Aggression, Depression, Attention Problems, Atypicality, Withdrawal) revealed that 5.5% were rated as being within the “At Risk” range and another 5.5% were rated as being within the “Clinically Significant” range. For overall child-reported

emotional symptoms (i.e., Social Stress, Anxiety, Depression, Sense of Inadequacy, Self-Esteem, Self-Reliance), 17.9% of children rated themselves as being within the “At Risk” range overall, but there were no participants who rated themselves as being in the “Clinically Significant” range.

Finally, with regard to Adaptive Behavior (i.e., Adaptability, Social Skills, Leadership Skills, Activities of Daily Living, Functional Communication), 11.1% of caregivers rated their children as being in the “At-Risk” range. On the child self-report, 17.9% of participants rated themselves in the “At Risk” range with regard to Adaptive Behavior (i.e., Relations with Parents, Interpersonal Relations, Self-Esteem, Self-Reliance).

Mean scores for family context variables (PAT 2.0 and PIP) indicate that this sample is similar to pediatric oncology samples in previous research (Kazak et al., 2004; Streisand et al., 2001) in terms of levels of family psychosocial stress and pediatric parenting stress. Analysis of the internal consistency of the PIP with the current sample revealed high reliability ($\alpha = 0.93$). Internal consistency could not be examined for the PAT 2.0 as the measure has only one scale. In addition, neither the PAT 2.0 nor the PIP has a standardized norming sample of caregivers of non-ill children because questions are specific to parenting a chronically ill child. On the PIP, caregivers reported greater overall frequency of distress than overall difficulty.

Mean scores on the BERS-2 (caregiver and child report) were within the average range, suggesting that the children in this sample did not differ in terms of overall emotional and behavioral strengths (e.g., resiliency) in comparison to the BERS-2

normative sample. Analysis of the internal consistency of the BERS-2 with the current sample revealed high reliability ($\alpha = 0.86$, caregiver report; $\alpha = 0.87$, child report).

Mean scores for illness-related variables (SOIS and PedsQL) indicate that this sample is similar to pediatric oncology samples in previous research in terms of levels of illness severity and physical functionality. Analysis of the internal consistency of the SOIS with the current sample revealed moderate reliability ($\alpha = 0.78$). Internal consistency could not be examined for the PedsQL as only one scale was administered.

Effects of Demographic Variables

The following demographic considerations were examined in terms of their potential effect on the independent and outcome variables: site (University of Texas M.D. Anderson Cancer Center (UTMDACC) or University of Minnesota Medical Center, Fairview (UMMC-F)), language (English or Spanish), age, age at diagnosis, gender, ethnicity, type of cancer, time since diagnosis, and staging (high-risk, standard-risk, low-risk). Results indicated no effect of site across most variables with the exception of higher self-reported child personal adjustment (BASC-2-SRP Personal Adjustment Composite) for patients at UMMC-F ($M = 57$; $SD = 3.59$) as compared to UTMDACC [$M = 48.1$; $SD = 90.1$; $F(1, 28) = 7.20$, $p < .05$; $r^2 = 0.22$].

Children with ALL ($M = 51.83$; $SD = 7.88$) and AML ($M = 53.00$; $SD = 7.07$) demonstrated higher self-reported adjustment (BASC-2-SRP Personal Adjustment Composite) in comparison to children with lymphoma [$M = 34.00$; $SD = 8.79$; $F(1, 28) = 8.43$, $p < .01$; $r^2 = 0.25$]. In addition, caregivers of children with ALL or AML reported higher parenting stress difficulties (PIP Difficulty score; $M = 109.07$; $SD = 32.45$ and M

= 104.00; $SD = 18.38$, respectively) in comparison to caregivers of children with lymphoma [$M = 24.00$; $SD = NA$; $F(1, 30) = 6.00$, $p < .05$; $r^2 = 0.18$]. However, these findings are questionable given the small number of participants with lymphoma.

There were also effects for the level of risk associated with the child's illness based on staging criteria, with children in higher-risk categories demonstrating fewer self-reported school problems (BASC-2-SRP-School Problems; $M = 42.10$; $SD = 4.15$) in comparison to children in low risk ($M = 63.50$; $SD = 26.16$) and standard risk groups [$M = 50.25$; $SD = 7.8$; $F(1, 16) = 10.92$, $p = .005$; $r^2 = 0.44$]. Children in high-risk staging also demonstrated fewer caregiver-reported externalizing problems (BASC-2-PRS-Externalizing; $M = 44.72$; $SD = 7.67$) in comparison to low risk ($M = 67.5$; $SD = 20.51$) and standard risk groups [$M = 47.00$; $SD = 10.94$; $F(1, 20) = 5.36$, $p < .05$; $r^2 = 0.23$]. They also demonstrated greater caregiver-reported resiliency (BERS Strength Index-Parent Report; $M = 107.00$; $SD = 16.61$) in comparison to low risk ($M = 72.50$; $SD = 14.85$) and standard risk groups [$M = 104.50$; $SD = 16.84$; $F(1, 16) = 5.03$, $p < .05$; $r^2 = 0.26$]. Again, these findings are questionable given the small amount of data obtained regarding staging risk. It is also important to note that staging data were missing for 16 participants, which may have impacted results.

Language demonstrated an effect on the level of self-reported child personal adjustment (BASC-2-SRP Personal Adjustment Composite), with lower adjustment reported by children in Spanish-speaking families ($M = 40.67$; $SD = 11.72$) in comparison to English-speaking families [$M = 51.84$; $SD = 7.85$; $F(1, 28) = 4.96$, $p < .05$; $r^2 = 0.16$]. There was also an effect for ethnicity on child-reported internalizing

symptoms and overall emotional adjustment [BASC-2-SRP Internalizing Composite and Emotional Symptoms Index; $F(1, 28) = 5.68, p < .05; r^2 = 0.18$, and $F(1, 28) = 8.00, p < .01; r^2 = 0.24$, respectively], with non-Caucasian children reporting higher symptoms than Caucasian children. Specifically, means and standard deviations for each group were as follows for the BASC-2-SRP-ESI as dependent variable: White/Caucasian ($M = 45.77; SD = 6.52$), Hispanic/Latino ($M = 53.25; SD = 7.67$), Black/African American ($M = 53.40; SD = 8.02$), American Indian/Alaska Native ($M = 57.5; SD = 12.02$). Means and standard deviations for each group were as follows for the BASC-2-SRP-Internalizing Composite as dependent variable: White/Caucasian ($M = 46.62; SD = 8.08$), Hispanic/Latino ($M = 51.63; SD = 8.77$), Black/African American ($M = 51.80; SD = 6.50$), American Indian/Alaska Native ($M = 62.00; SD = 12.73$). Data regarding these dependent variables were not available for some children as they were too young to complete the self-report BASC-2 questionnaire. In addition, there appears to be a possible outlier among the group of American Indian/Alaska Native children; this particular child appeared to be experiencing many psychosocial stressors unrelated to his/her cancer treatment.

There was a significant effect for age on both frequency and difficulty of parenting stress [PIP Frequency (F-PIP) and Difficulty scores (D-PIP)], with caregivers of younger children reporting greater parenting stress [$F(1, 30) = 7.59, p = .01; r^2 = 0.21$, and $F(1, 30) = 11.49, p < .01; r^2 = 0.29$, respectively]. The child's age at the time of his/her diagnosis was related to several variables, including: the difficulty of parenting stress [PIP Difficulty score; $F(1, 30) = 4.74, p < .05; r^2 = 0.15$], and caregiver-reported

child symptoms in both externalizing, internalizing, and overall areas [BASC-2-PRS Externalizing Composite, Internalizing Composite, and Behavioral Symptoms Index; $F(1, 30) = 4.73, p < .05; r^2 = 0.12$, $F(1, 30) = 4.75, p < .05; r^2 = 0.12$, and $F(1, 30) = 4.19, p < .05; r^2 = 0.11$, respectively]. These findings indicated that when children were diagnosed at a younger age, this is related to greater parenting stress difficulty, as well as greater number of child emotional and behavioral difficulties (caregiver-reported). Related to this is the variable of time since diagnosis, which was also shown to be related to caregiver-reported child symptoms in both externalizing and overall areas [BASC-2-PRS Externalizing Composite and Behavioral Symptoms Index; $F(1, 36) = 5.02, p < .05; r^2 = 0.13$, and $F(1, 36) = 4.72, p < .05; r^2 = 0.12$, respectively]. These findings indicate that when children were in treatment for a longer period of time, this was related to a greater number of child emotional and behavioral difficulties (by caregiver-report).

These results indicated that there may be an interaction effect between age at diagnosis and time since diagnosis, which required examination. Thus, interaction effects were created by centering each variable to be analyzed, and then entering this interaction term in the regression model as the last term in the analysis. According to the previous analysis, caregiver-reported child externalizing behaviors and overall behavioral symptoms (BASC-2-PRS-Externalizing and BASC-2-PRS-BSI, respectively) were each related to age at diagnosis and time since diagnosis. Thus, each of the independent variables was centered, and the following interaction term was created: Age at Diagnosis x Time Since Diagnosis. Separate multiple regression analyses were run

with each variable as follows. In the first analysis, Age at Diagnosis was entered as the first-step independent variable predicting the dependent variable of BASC-2-PRS-Externalizing. Then, in the second step, the interaction term Age at Diagnosis x Time Since Diagnosis was added as another independent variable. Results of this analysis indicated that the interaction term did not demonstrate significant effects above what could be explained by the first relationship alone [$F(2, 33) = 2.77, p = .08; r^2 = 0.14$]. In the second analysis, Age at Diagnosis was again entered as the first-step independent variable, this time predicting the dependent variable of BASC-2-PRS-BSI. In the second step, the interaction term Age at Diagnosis x Time Since Diagnosis was again added as an independent variable. Again, results of this analysis indicated that the interaction term did not demonstrate significant effects above what could be explained by the first relationship alone [$F(2, 33) = 2.86, p = .07; r^2 = 0.15$]. (See Tables IV and V for regression summaries). These results indicate that each of these variables is related to child adjustment separately from one another, and they do not have a combined effect.

Table IV. Summary of Linear Regression Analyses for Variables Predicting BASC-2-PRS-Externalizing

Variable	<i>B</i>	<i>SE B</i>	β
Step 1			
Age at Diagnosis	-0.68	0.31	-0.35
Step 2			
Age at Diagnosis x Time Since Diagnosis	-0.01	0.10	-0.15

Note: BASC-2-PRS-Externalizing = Behavior Assessment Scale for Children – Parent Report Scale – Externalizing Composite

Table V. Summary of Linear Regression Analyses for Variables Predicting BASC-2-PRS-BSI

Variable	<i>B</i>	<i>SE B</i>	β
Step 1			
Age at Diagnosis	-0.55	0.27	-0.33
Step 2			
Age at Diagnosis x Time Since Diagnosis	-0.01	0.08	-0.21

Note: BASC-2-PRS-BSI = Behavior Assessment Scale for Children – Parent Report Scale – Behavioral Symptoms Index

There was a significant effect for gender on caregiver-reported child internalizing symptoms and overall behavioral symptoms (BASC-2-PRS Internalizing Composite and

Behavioral Symptoms Index), with caregivers reporting greater internalizing symptoms among girls ($M = 60.76$; $SD = 10.60$) than boys [$M = 50.42$; $SD = 9.65$; $F(1, 36) = 9.40$, $p < .01$; $r^2 = 0.22$], as well as greater overall behavioral symptoms among girls ($M = 52.47$; $SD = 8.52$) in comparison to boys [$M = 46.63$; $SD = 8.13$; $F(1, 36) = 4.42$, $p < .05$; $r^2 = 0.12$]. (See Table VI for significant regression analyses of demographic variables).

Table VI. Summary of Linear Regression Analyses for Demographic Variables

Variable	<i>B</i>	<i>SE B</i>	β
Data Collection Site and Personal Adjustment Child Report	8.9	3.32	0.47
Type of Cancer and Personal Adjustment Child Report	-5.37	1.85	-0.5
Type of Cancer and Difficulty of Parenting Stress	-24.54	10.02	-0.42
Staging and School Problems, Child Report	-10.06	3.05	-0.66
Staging and Externalizing Problems, Parent Report	-8.18	3.53	-0.48
Staging and Resiliency, Parent Report	13.56	6.05	0.51
Language Spoken and Personal Adjustment Child Report	-11.17	5.02	-0.40

Table VI. Continued

Variable	<i>B</i>	<i>SE B</i>	β
Ethnicity and Internalizing Problems, Child Report	3.63	1.52	0.42
Ethnicity and Emotional Symptoms Index, Child Report	3.84	1.36	0.49
Age and Frequency of Parenting Stress	-3.96	1.44	-0.46
Age and Difficulty of Parenting Stress	-4.72	1.39	-0.54
Age at Diagnosis and Difficulty of Parenting Stress	-2.57	1.18	-0.38
Age at Diagnosis and Externalizing Problems, Parent Report	-0.68	0.31	-0.35
Age at Diagnosis and Internalizing Problems, Parent Report	-0.76	0.35	-0.35
Age at Diagnosis and Behavioral Symptoms Index, Parent Report	-0.55	0.27	-0.33
Time Since Diagnosis and Externalizing Problems, Parent Report	0.13	0.06	0.36
Time Since Diagnosis and Behavioral Symptoms Index, Parent Report	0.11	0.06	0.35
Gender and Internalizing Symptoms, Parent Report	-10.34	3.37	-0.47

Table VI. Continued

Variable	<i>B</i>	<i>SE B</i>	β
Gender and Behavioral Symptoms Index, Parent Report	-5.84	2.78	-0.34

Contribution of Variance

Research Question 1:

To what extent are illness-related factors related to child adjustment? This question can be viewed in the following models, with the independent variables of Child-Reported Physical Health and Functioning [Pediatric Quality of Life Scale (PedsQL), age-appropriate self-report form, Physical Health and Functioning composite score], Parent-Reported Physical Health and Functioning [Pediatric Quality of Life Scale (PedsQL), child age-appropriate caregiver-report form, Physical Health and Functioning composite score], and Medical Staff-Reported Severity of Illness [Severity of Illness Scale (SOIS) composite score], and the dependent variables of Child-Reported Adjustment [Behavior Assessment Scale for Children-2 (BASC-2), age-appropriate self-report form, composite scores: School Problems, Internalizing Symptoms, Inattention/Hyperactivity Symptoms, Emotional Symptoms Index, and Personal Adjustment Composite] and Parent-Reported Adjustment [Behavior Assessment Scale for Children-2 (BASC-2), child age-appropriate caregiver-report form, composite scores: Externalizing Symptoms, Internalizing Symptoms, Behavioral Symptoms Index, and

Adaptive Behavior Composite]. (See Figures 2-10.) The research question was answered by examining the correlations between all identified variables. Results demonstrated no statistically significant effect of illness-related factors on child adjustment.

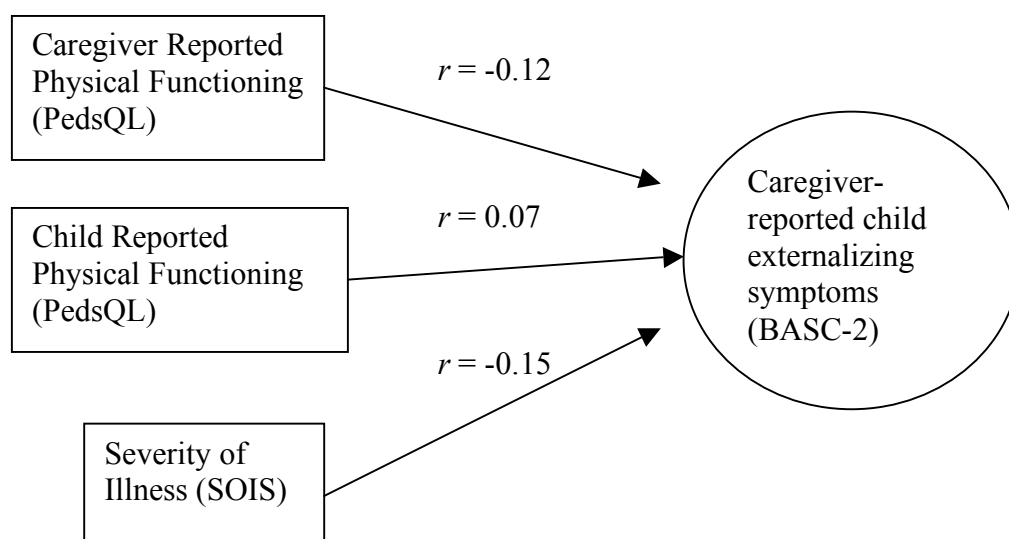


Figure 2. Correlation coefficients: Illness-related variables and caregiver-reported child externalizing symptoms.

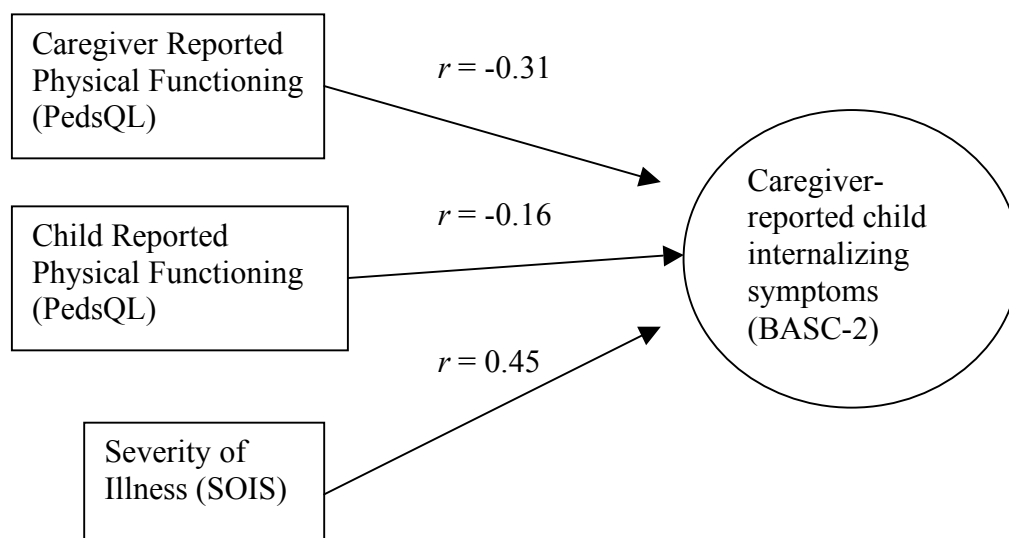


Figure 3. Correlation coefficients: Illness-related variables and caregiver-reported child internalizing symptoms.

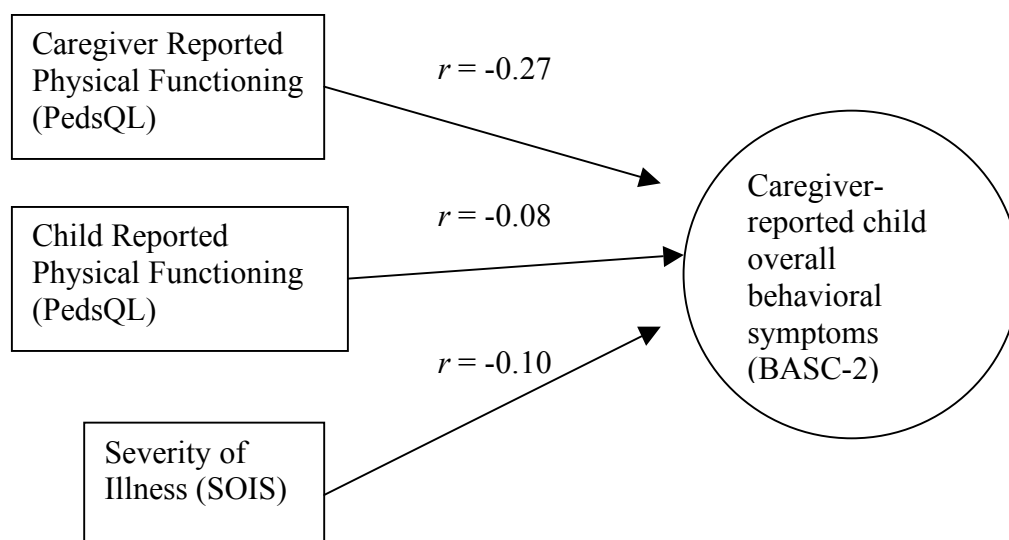


Figure 4. Correlation coefficients: Illness-related variables and caregiver-reported child overall behavioral symptoms.

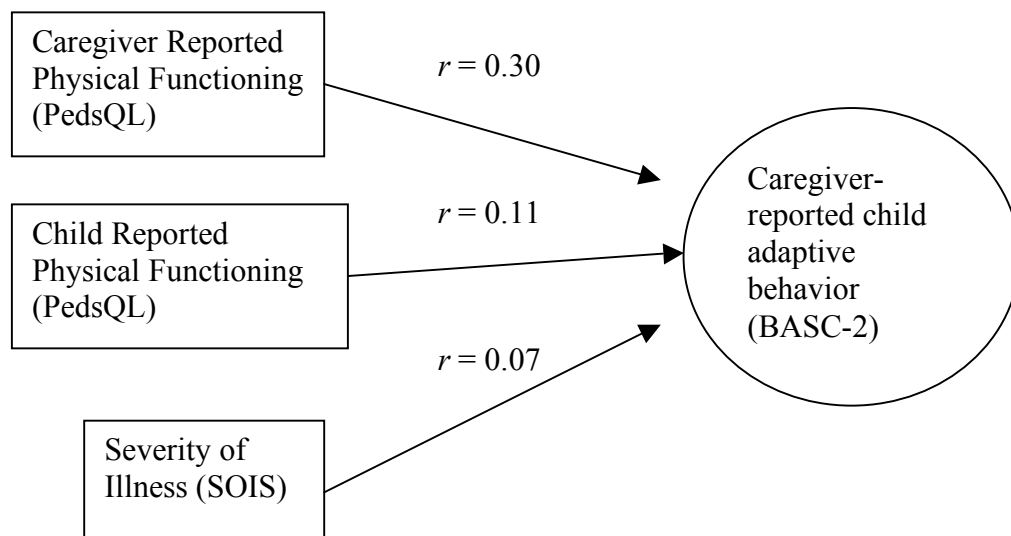


Figure 5. Correlation coefficients: Illness-related variables and caregiver-reported child adaptive behavior.

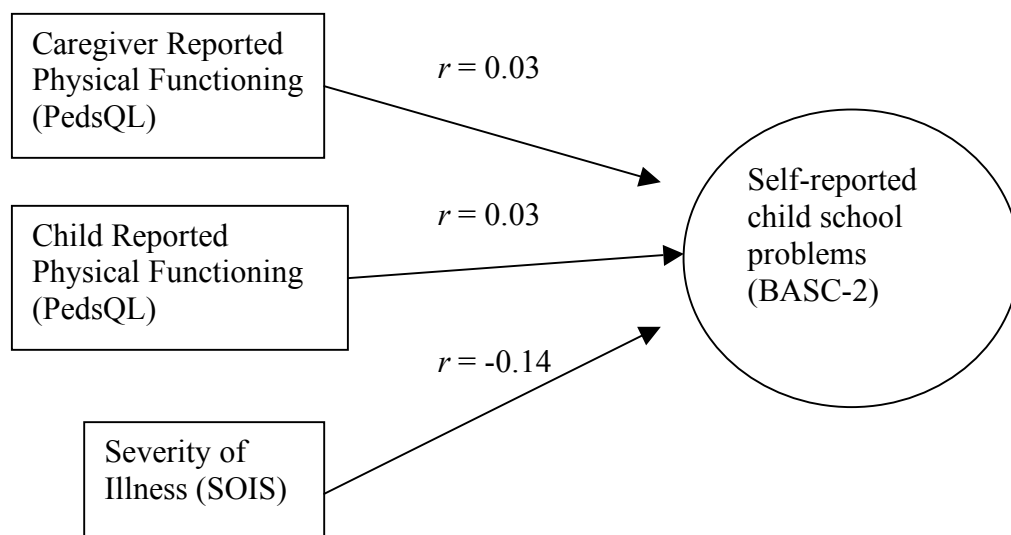


Figure 6. Correlation coefficients: Illness-related variables and self-reported child school problems.

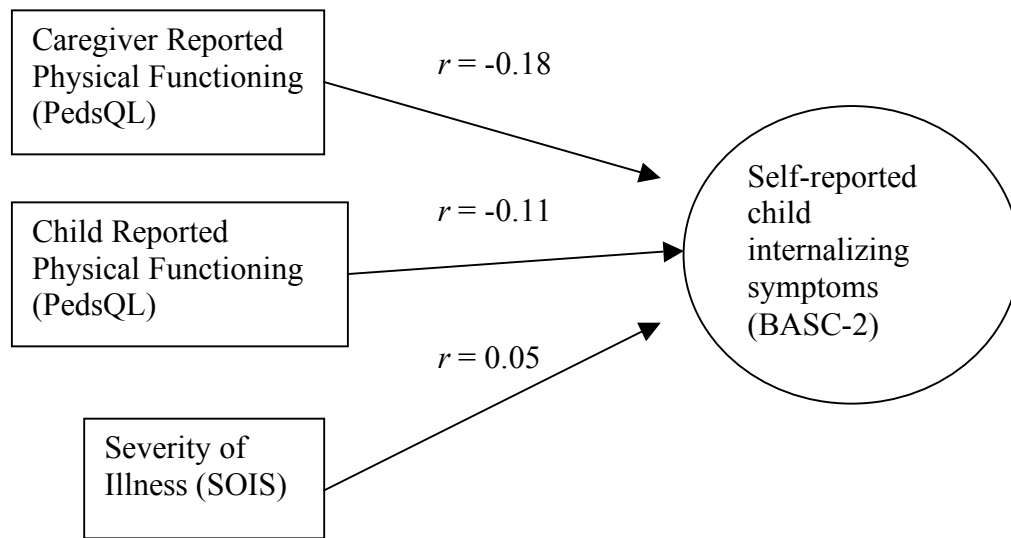


Figure 7. Correlation coefficients: Illness-related variables and self-reported child internalizing symptoms.

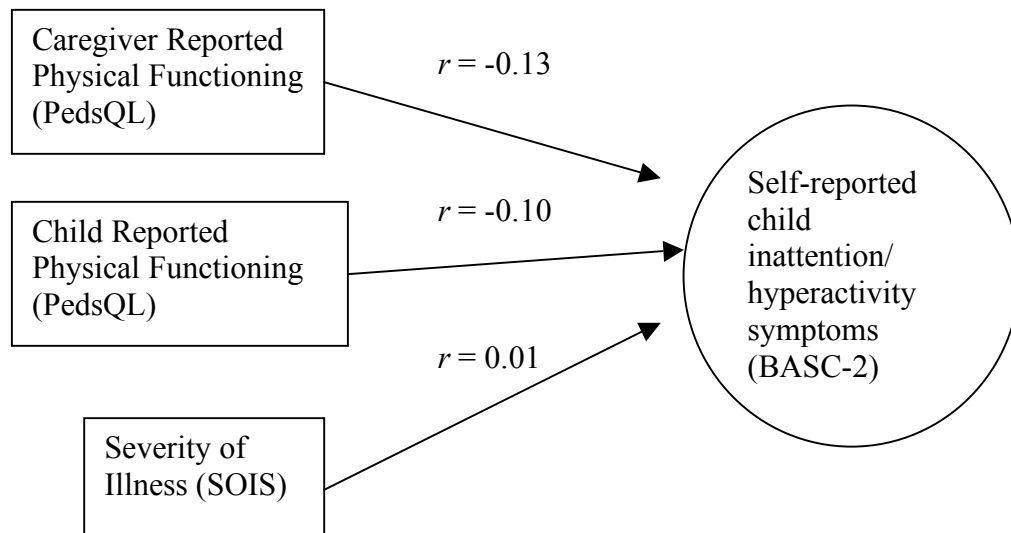


Figure 8. Correlation coefficients: Illness-related variables and self-reported child inattention/hyperactivity symptoms.

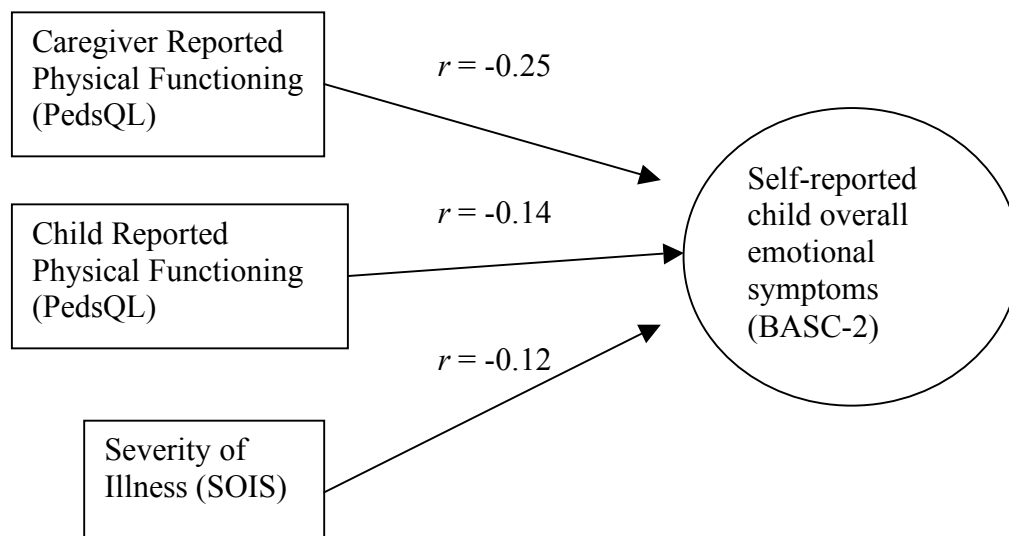


Figure 9. Correlation coefficients: Illness-related variables and self-reported child overall emotional symptoms.

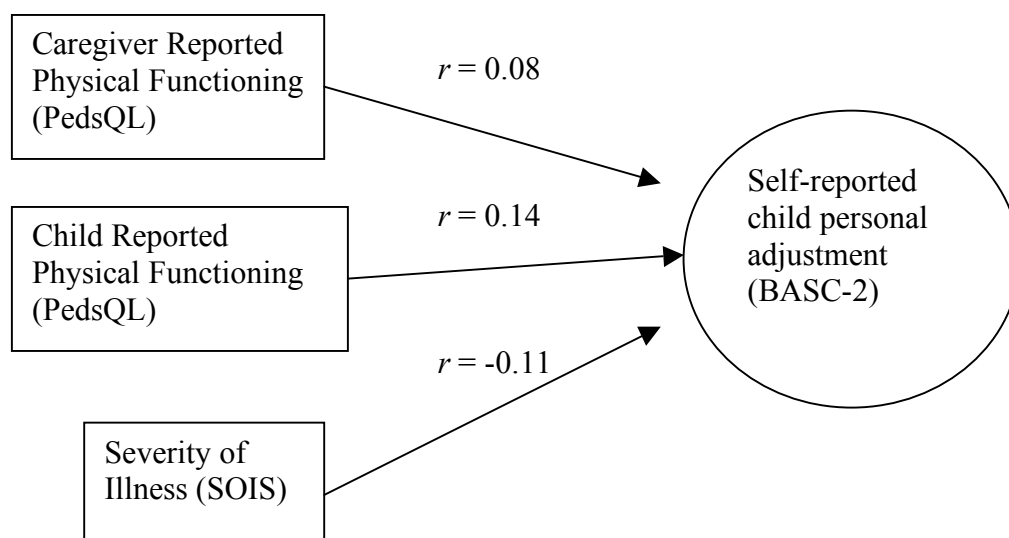


Figure 10. Correlation coefficients: Illness-related variables and self-reported child personal adjustment.

Research Question 2:

Next, to answer the question: **Does relapse status significantly affect child adjustment**, correlational analyses were run, including all outcome variables defined above and the independent variable of relapse status (presence of relapse, no presence of relapse). Again, results demonstrated no statistically significant effect of relapse status on child adjustment with r values ranging from -0.17 to 0.17 .

Research Question 3:

Finally, to answer the question: **Does the stage of treatment affect child adjustment**, correlational analyses were run, including all outcome variables defined above and the independent variable of treatment status (induction/intensification, maintenance). In this final analysis, results also demonstrated no statistically significant effect of treatment status on child adjustment with r values ranging from -0.34 to 0.23 . Relationships approaching significance included those between treatment status and both child-reported inattention/hyperactivity symptoms ($r = -0.34$) and child-reported personal adjustment ($r = 0.23$).

Research Question 4:

To what extent is family context related to child adjustment? The variables in this question can be seen in the following models. (See Figures 11-19.) Caregiver-reported Frequency of Parental Emotional Distress [Pediatric Inventory for Parents (PIP) Frequency Composite], caregiver-reported Difficulty of Parental Emotional Distress [Pediatric Inventory for Parents (PIP) Difficulty Composite], and caregiver-reported Family Psychosocial Risk [Psychosocial Assessment Tool, 2nd Version (PAT 2.0) Total

Score] will serve as independent variables, while caregiver- and child-reported adjustment (BASC-2, composites detailed previously) will serve as dependent variables. The research question was answered using correlation procedures.

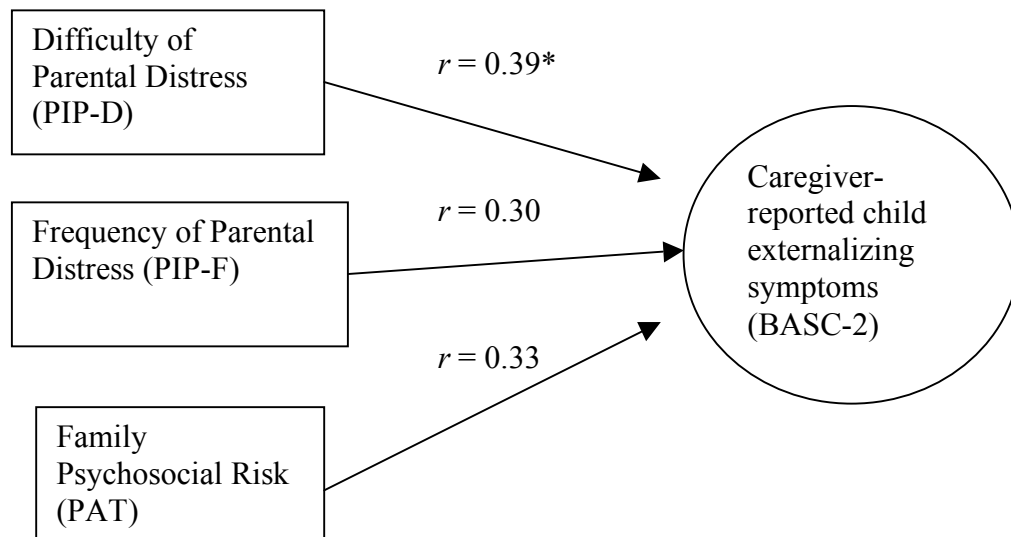


Figure 11. Correlation coefficients: Family context variables and caregiver-reported child externalizing symptoms. ($*p < .05$)

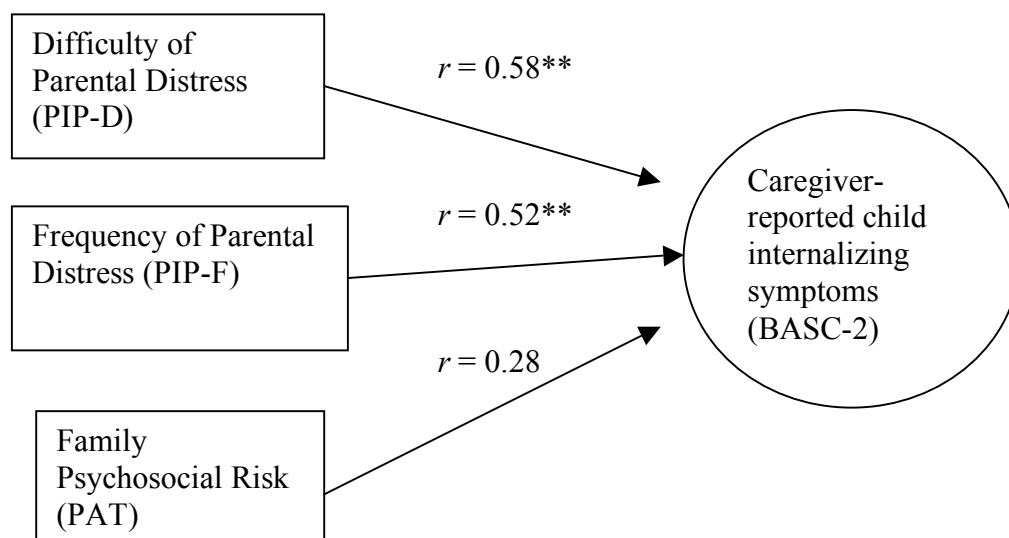


Figure 12. Correlation coefficients: Family context variables and caregiver-reported child internalizing symptoms. ($**p < .01$)

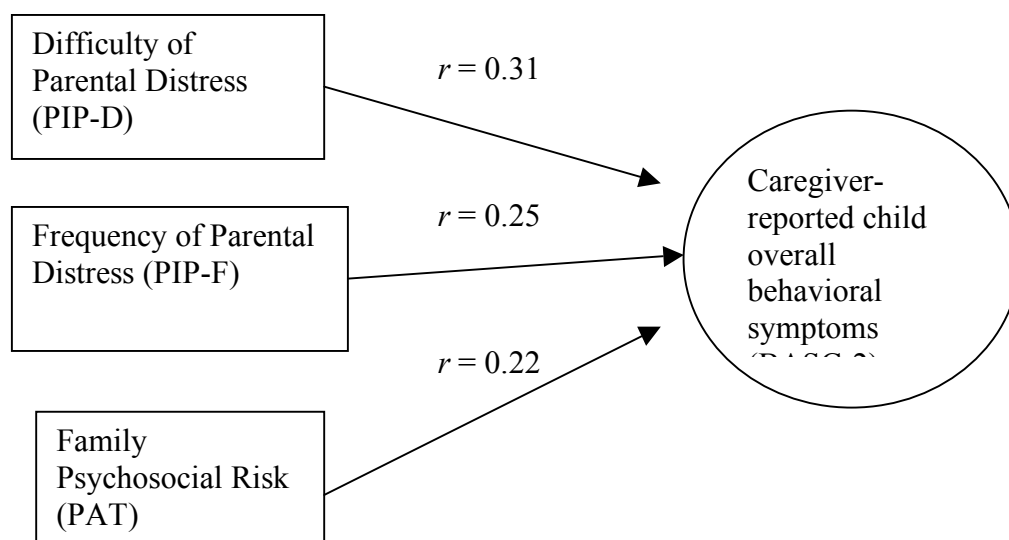


Figure 13. Correlation coefficients: Family context variables and caregiver-reported child overall behavioral symptoms.

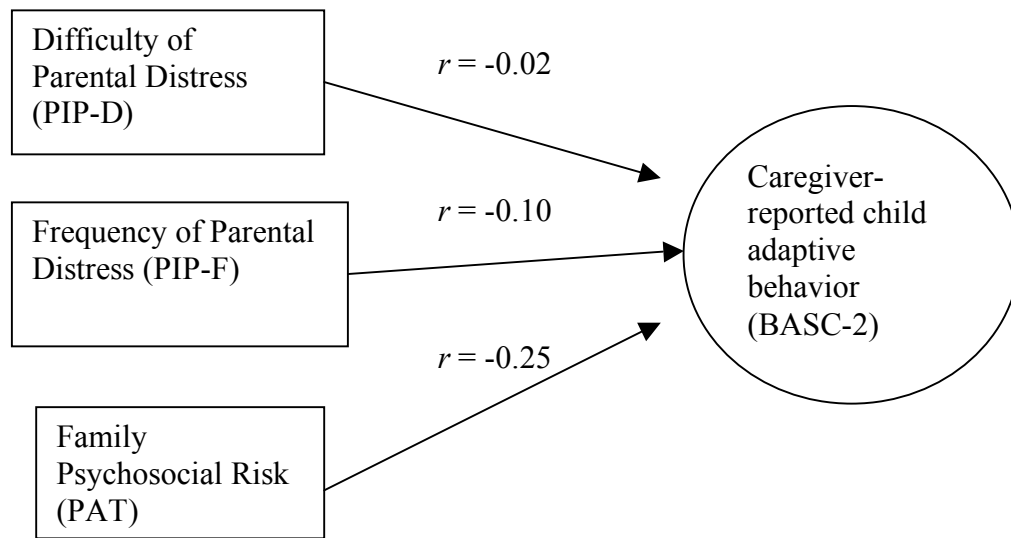


Figure 14. Correlation coefficients: Family context variables and caregiver-reported child adaptive behavior.

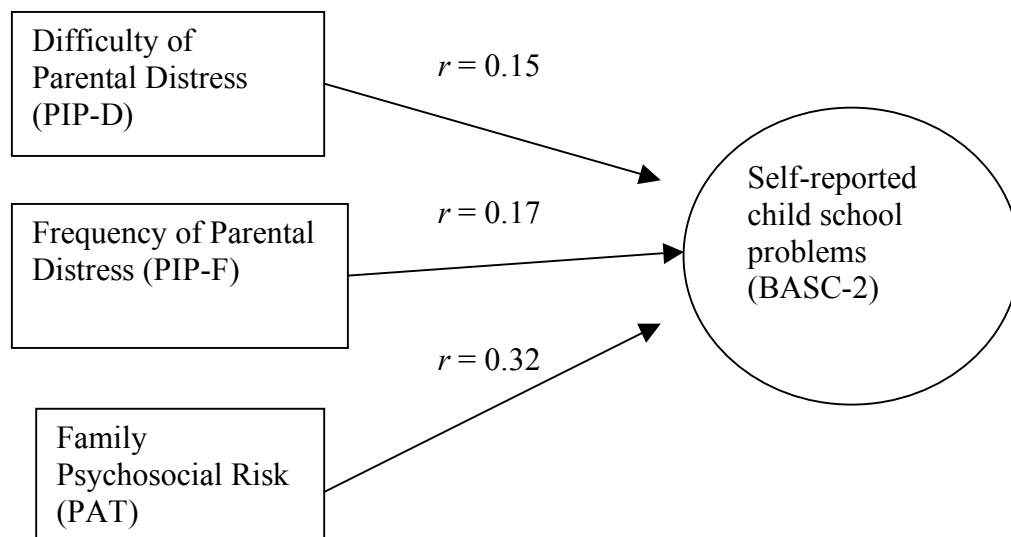


Figure 15. Correlation coefficients: Family context variables and self-reported child school problems.

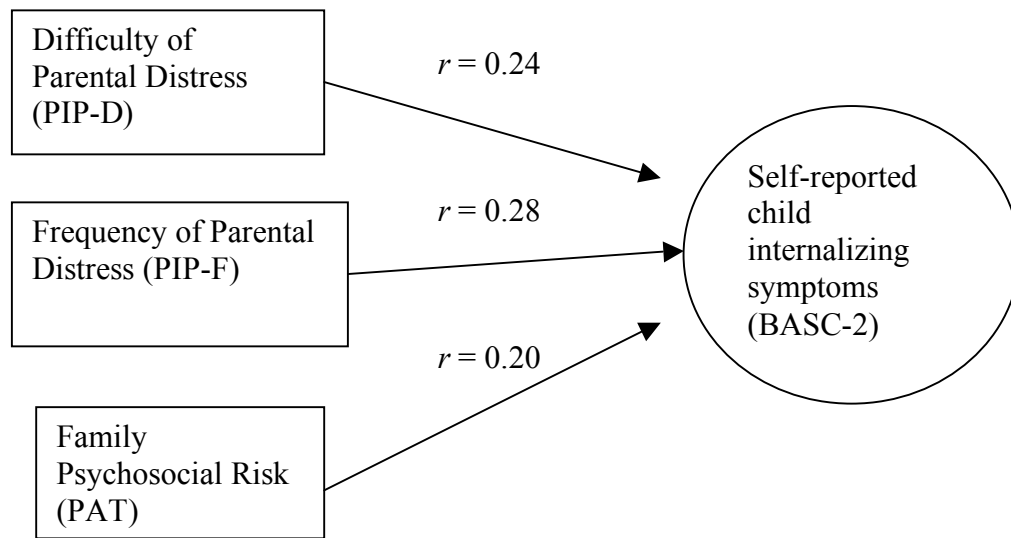


Figure 16. Correlation coefficients: Family context variables and self-reported child internalizing symptoms.

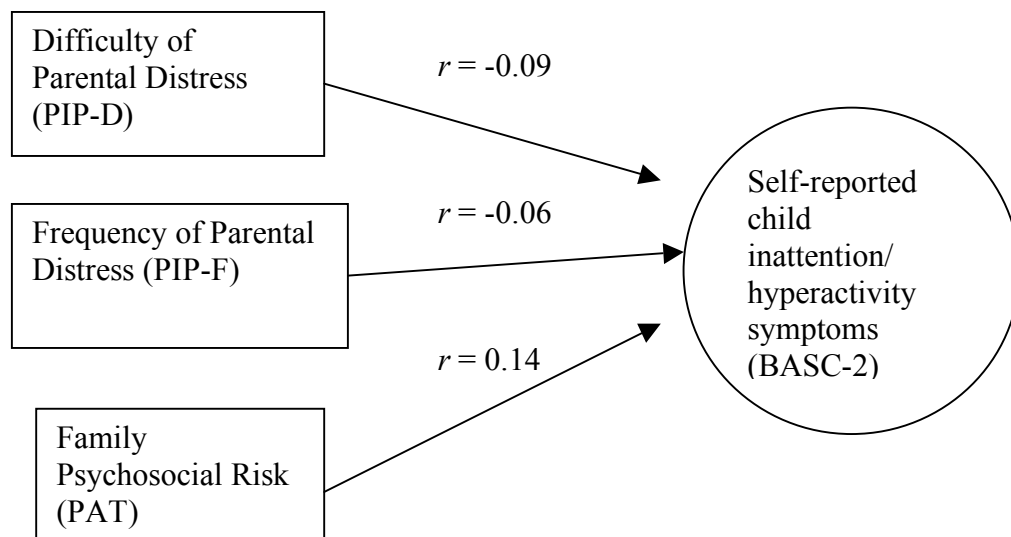


Figure 17. Correlation coefficients: Family context variables and self-reported child inattention/hyperactivity symptoms.

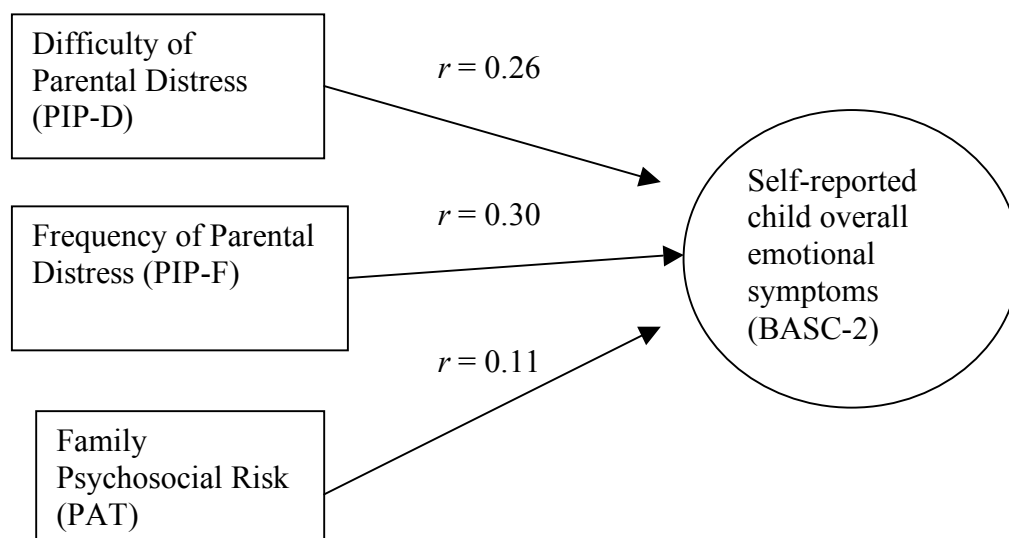


Figure 18. Correlation coefficients: Family context variables and self-reported child overall emotional symptoms.

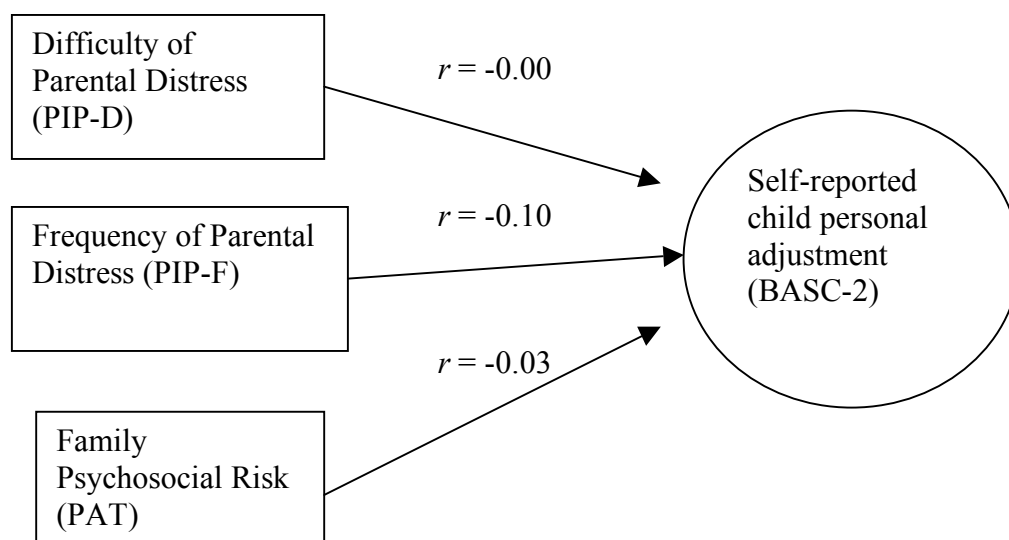


Figure 19. Correlation coefficients: Family context variables and self-reported child personal adjustment.

Caregiver-reported Family Psychosocial Risk (PAT 2.0) was not significantly related to child outcome measures. However, pediatric parenting stress (PIP) was related to child adjustment through several direct relationships. Specifically, there were effects for Frequency of parental distress on caregiver-reported child internalizing symptoms [$F(1, 30) = 10.12, p < .01; r^2 = 0.27$], Difficulty of parental distress on caregiver-reported child internalizing symptoms [$F(1, 30) = 14.33, p = .001; r^2 = 0.34$], and Difficulty of parental distress on caregiver-reported child externalizing symptoms [$F(1, 30) = 4.89, p < .05; r^2 = 0.15$]. Interestingly, PAT 2.0 scores were directly related to Pediatric Parenting Stress (PIP), perhaps indicating that family psychosocial risk has an indirect effect on child adjustment through its effect on parenting distress. (See Table VII for significant regression analyses of family context variables).

Table VII. Summary of Linear Regression Analyses for Family Context Variables

Variable	<i>B</i>	<i>SE B</i>	β
Frequency of Parenting Stress And Internalizing Symptoms Parent Report	0.17	0.05	0.52
Difficulty of Parenting Stress And Internalizing Symptoms Parent Report	0.19	0.05	0.58
Difficulty of Parenting Stress And Externalizing Symptoms Parent Report	0.11	0.05	0.39

Research Question 5:

To what extent is child resiliency related to child adjustment? The variables in this question can be seen in the following models. (See Figures 20-28.) Child-reported Overall Strengths [Behavioral and Emotional Rating Scale-2nd Edition (BERS-2), Youth Report Form, Strength Index] and caregiver-reported Overall Strengths [Behavioral and Emotional Rating Scale-2nd Edition (BERS-2), Parent Report Form, Strength Index] served as independent variables, and Child-reported Adjustment and Caregiver-reported Adjustment were dependent variables (BASC-2, composite scores as detailed previously).

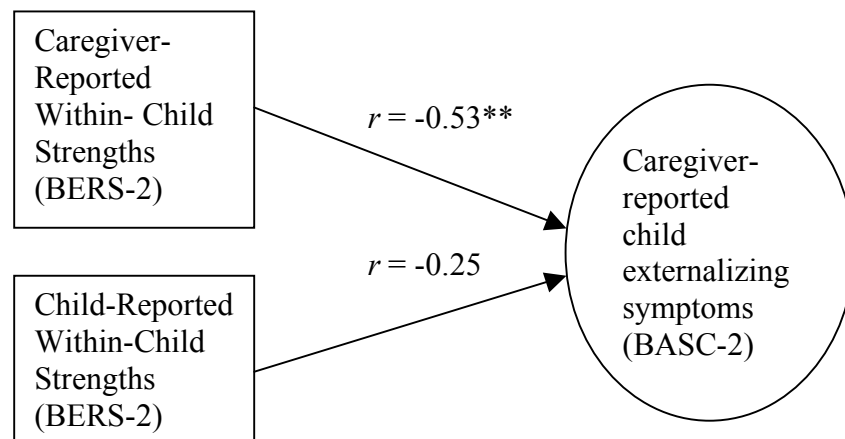


Figure 20. Correlation coefficients: Child resiliency variables and caregiver-reported child externalizing symptoms. (** $p < .01$)

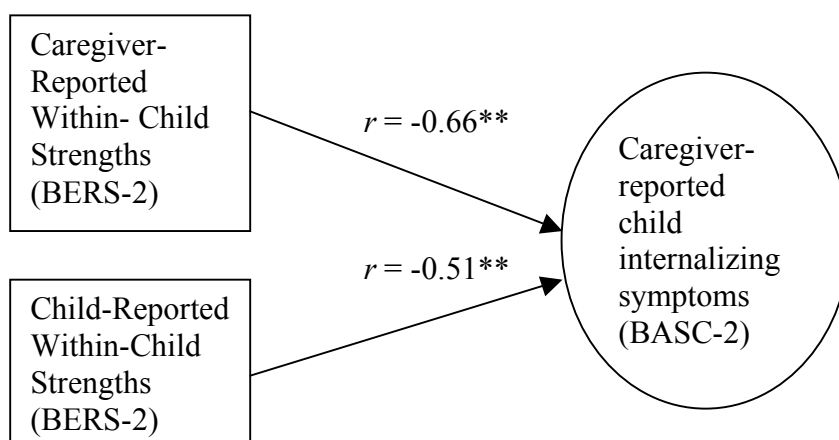


Figure 21. Correlation coefficients: Child resiliency variables and caregiver-reported child internalizing symptoms. ($**p < .01$)

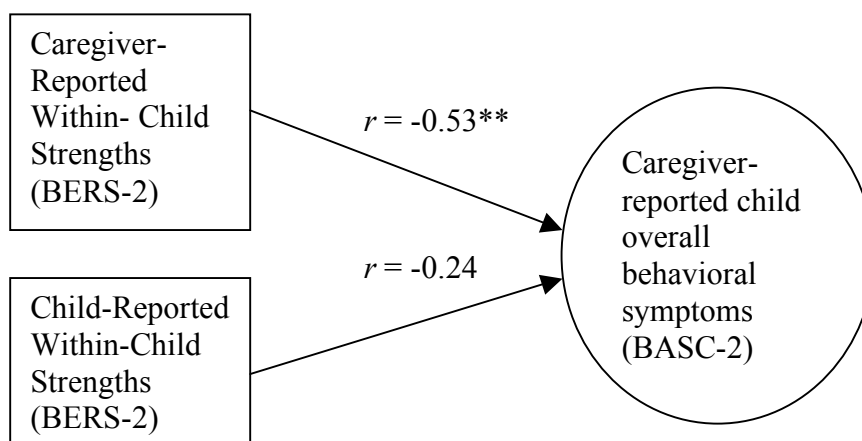


Figure 22. Correlation coefficients: Child resiliency variables and caregiver-reported overall behavioral symptoms. ($**p < .01$)

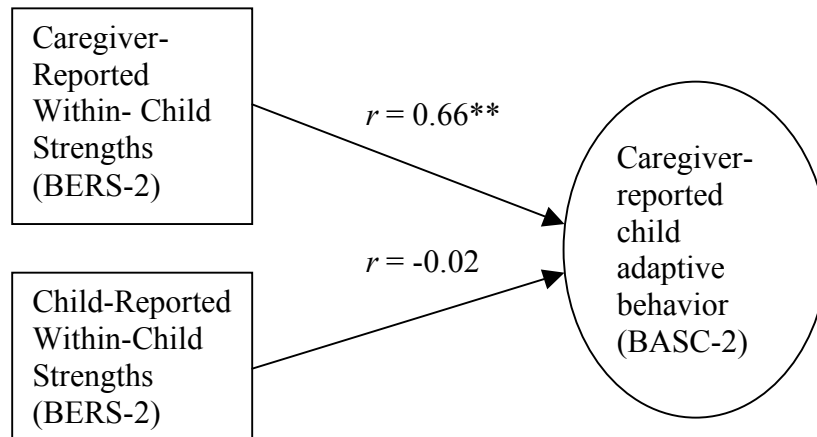


Figure 23. Correlation coefficients: Child resiliency variables and caregiver-reported child adaptive behavior. ($**p < .01$)

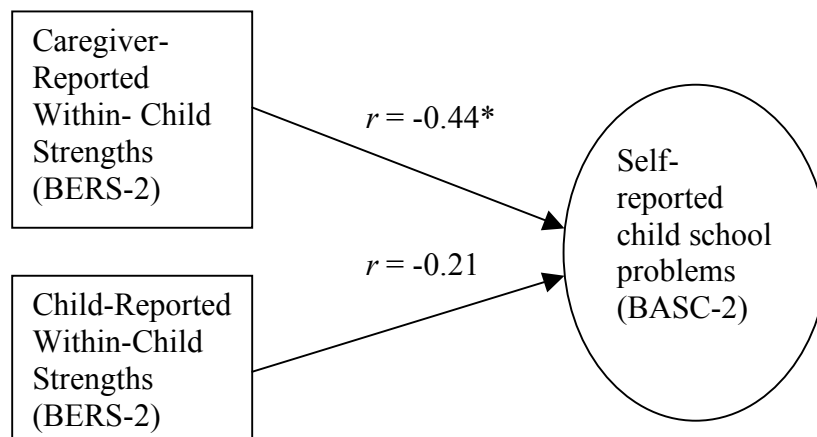


Figure 24. Correlation coefficients: Child resiliency variables and self-reported child school problems. ($*p < .05$)

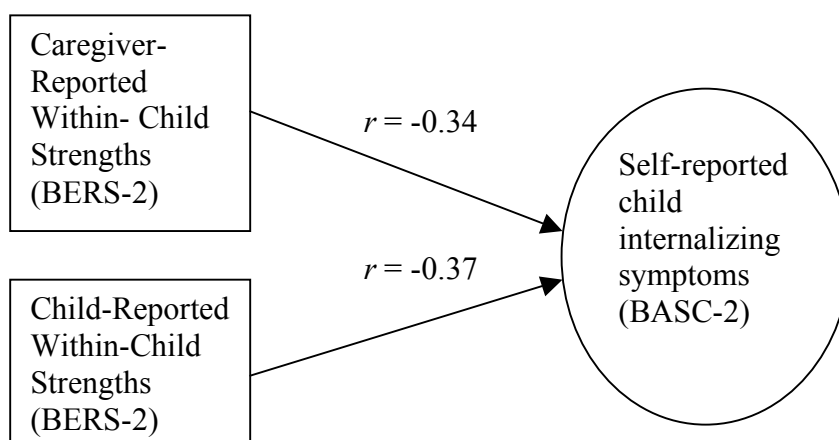


Figure 25. Correlation coefficients: Child resiliency variables and self-reported child internalizing symptoms.

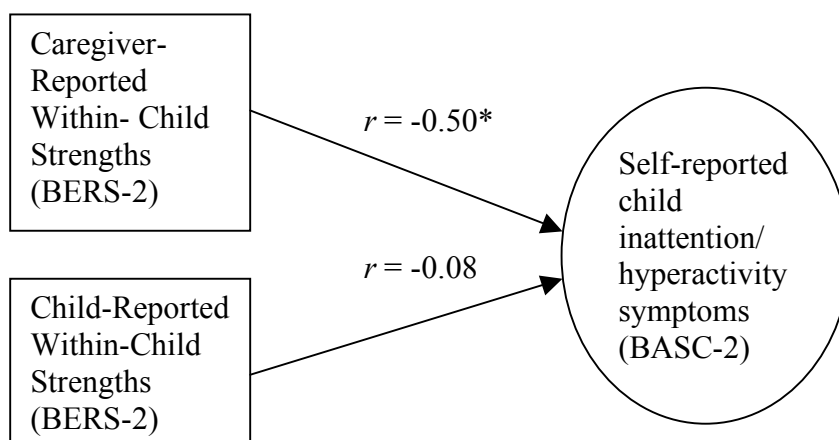


Figure 26. Correlation coefficients: Child resiliency variables and self-reported child inattention/hyperactivity symptoms. (* $p < .05$)

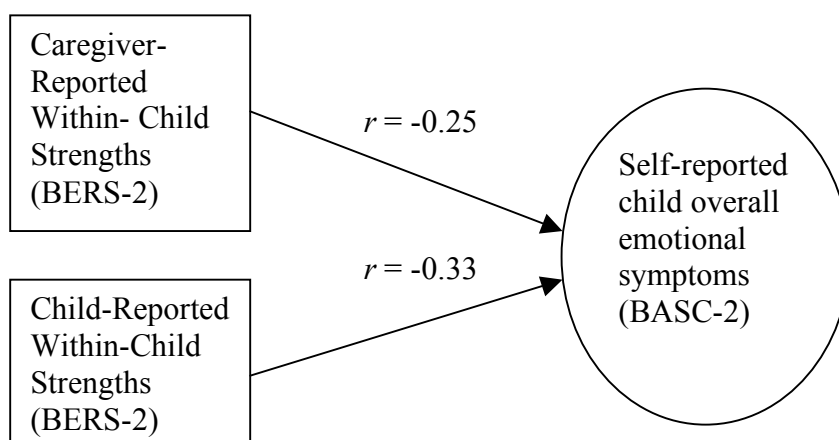


Figure 27. Correlation coefficients: Child resiliency variables and self-reported child overall emotional symptoms.

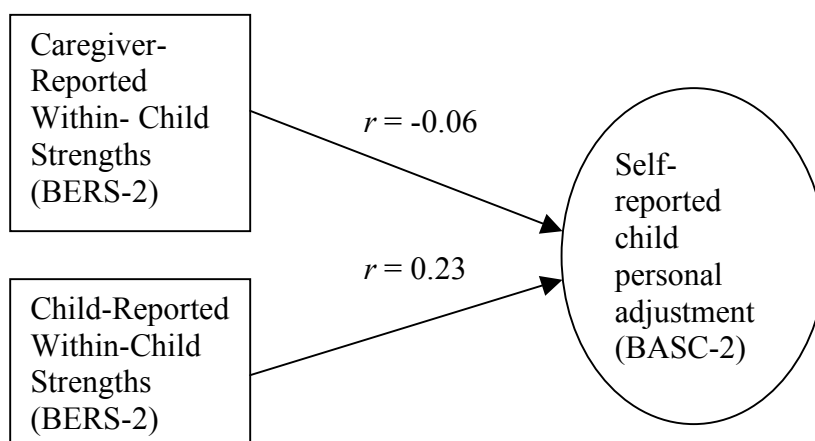


Figure 28. Correlation coefficients: Child resiliency variables and self-reported child personal adjustment.

Correlational analyses revealed that caregiver-reported child strengths were significantly negatively related to several outcome variables, including caregiver-reported child externalizing symptoms [$F(1, 29) = 10.31, p < .005; r^2 = 0.28$], caregiver-reported overall child adjustment [$F(1, 29) = 10.65, p < .005; r^2 = 0.28$], child-reported school problems [$F(1, 25) = 5.62, p < .05; r^2 = 0.20$], and child-reported inattention/hyperactivity [$F(1, 25) = 7.61, p < .05; r^2 = 0.25$]. Caregiver-reported child strengths were significantly positively related to caregiver-reported child adaptive skills [$F(1, 29) = 20.75, p < .001; r^2 = 0.44$]. In addition, child-reported strengths were significantly negatively correlated with caregiver-reported child internalizing symptoms [$F(1, 34) = 11.18, p < .005; r^2 = 0.26$]. (See Table VIII for significant regression analyses of within-child variables).

Table VIII. Summary of Linear Regression Analyses for Resiliency Variables

Variable	<i>B</i>	<i>SE B</i>	β
Resiliency, Parent Report, and Externalizing Symptoms, Parent Report	-0.3	0.1	-0.53
Resiliency, Parent Report, and Adaptive Behavior, Parent Report	0.36	0.08	0.66
Resiliency, Parent Report, and School Problems, Parent Report	-0.27	0.11	-0.44

Table VIII. Continued

Variable	<i>B</i>	<i>SE B</i>	β
Resiliency, Parent Report, and Inattention/Hyperactivity, Child Report	-0.22	0.08	-0.50
Resiliency, Parent Report, and Behavioral Symptoms Index, Parent Report	-0.26	0.08	-0.53
Resiliency, Child Report, and Internalizing Symptoms, Parent Report	-0.32	0.1	-0.51

Research Question 6:

To what extent does parental distress moderate the relationship between caregiver report of child adjustment and child report of child adjustment? Parental distress as measured by the Frequency of Parental Emotional Distress and Difficulty of Parental Emotional Distress on the PIP was to be examined as a moderator affecting the correlation between Caregiver-report on the BASC-2 and Child-report on the BASC-2; however, due to the small sample size in this study, a moderator analysis was not recommended. Alternatively, interaction effects were created by centering each variable to be analyzed, and then entering this interaction term in the regression model as the last term in the analysis. According to a previous analysis, the frequency and difficulty of parenting stress (F-PIP and D-PIP, respectively) were each related to caregiver-reported

child internalizing problems (BASC-2-PRS-Internalizing). In addition, D-PIP was related to caregiver-reported child externalizing problems (BASC-2-PRS-Externalizing). Thus, each of these four variables was centered, and the following interaction terms were created: F-PIP x BASC-2-PRS-Internalizing, D-PIP x BASC-2-PRS-Internalizing, and D-PIP x BASC-2-PRS-Externalizing. In the correlational analyses, it was determined that BASC-2-PRS-Internalizing was significantly related to child-reported internalizing symptoms (BASC-2-SRP-Internalizing; $r = 0.60, p = .001$), and BASC-2-PRS-Externalizing was significantly related to child-reported school problems (BASC-2-SRP-SchlProbs; $r = 0.63, p < .001$). (See Table IX for correlations).

Table IX. Intercorrelations Between Parent- and Child-Report of Adjustment

Composite Scales	BASC-2-PRS-Externalizing	BASC-2-PRS-Internalizing
BASC-2-SRP-Internalizing	0.42*	0.60**
BASC-2-SRP-School Problems	0.63**	0.43*

* $p < .05$

** $p < .01$

Thus, separate multiple regression analyses were run with each variable as follows. In the first analysis, BASC-2-PRS-Internalizing was entered as the first-step independent variable predicting the dependent variable of BASC-2-SRP-Internalizing. Then, in the second step, the interaction term F-PIP x BASC-2-PRS-Internalizing was

added as another independent variable. Results of this analysis indicated that the interaction term did not demonstrate significant effects above what could be explained by the first relationship alone. In the second analysis, BASC-2-PRS-Internalizing was again entered as the first-step independent variable predicting the dependent variable of BASC-2-SRP-Internalizing. Then, in the second step, the interaction term D-PIP x BASC-2-PRS-Internalizing was added as another independent variable. Again, results of this analysis indicated that the interaction term did not demonstrate significant effects above what could be explained by the first relationship alone. These results indicate that parental distress does not have a significant effect on a caregiver's ability to rate child internalizing symptoms similar to the child's own ratings.

In the final analysis, BASC-2-PRS-Externalizing was entered as the first-step independent variable predicting the dependent variable of BASC-2-SRP-School Problems. Then, in the second step, the interaction term F-PIP x BASC-2-PRS-Externalizing was added as another independent variable. Results of this analysis indicated that the interaction term did demonstrate significant effects above what could be explained by the first relationship alone [$F(1, 28) = 13.85, p < .001; r^2 = 0.15$], indicating that the difficulty of parenting stress may impact caregivers' ratings of child externalizing symptoms in comparison to children's own ratings. (See Tables X and XI for regression summaries).

Table X. Summary of Linear Regression Analyses for Variables Predicting BASC-2-SRP-Internalizing

Variable	<i>B</i>	<i>SE B</i>	β
Step 1			
BASC-2-PRS-Internalizing	0.49	0.13	0.60
Step 2			
F-PIP x BASC-2-PRS-Internalizing	0.01	0.0	0.20
<i>Second Analysis</i>			
	<i>B</i>	<i>SE B</i>	β
Step 1			
BASC-2-PRS-Internalizing	0.49	0.13	0.60
Step 2			
D-PIP x BASC-2-PRS-Internalizing	0.0	0.01	0.10

Note: BASC-2-PRS-Internalizing = Behavior Assessment Scale for Children – Parent Report Scale – Internalizing Composite; F-PIP = Frequency Score – Pediatric Inventory for Parents; D-PIP = Difficulty Score – Pediatric Inventory for Parents

Table XI. Summary of Hierarchical Regression Analyses for Variables Predicting BASC-2-SRP-School Problems

Variable	<i>B</i>	<i>SE B</i>	β
Step 1			
BASC-2-PRS-Externalizing	0.63	0.16	0.63
Step 2			
F-PIP x BASC-2-PRS-Externalizing	0.01	0.0	0.46

Note: BASC-2-PRS-Externalizing = Behavior Assessment Scale for Children – Parent Report Scale – Externalizing Composite

CHAPTER V

DISCUSSION: SUMMARY AND CONCLUSIONS

The primary purpose of this study was to investigate the relations among psychosocial adjustment, illness-related factors (i.e., severity of illness, physical functionality), family context factors (i.e., parenting stress, family psychosocial risk), and within-child factors (i.e., child resiliency) in children with cancer. Previous research on the psychosocial adjustment of children with cancer has suggested that they typically demonstrate similar psychosocial adjustment in comparison to same-age peers. These results have been somewhat inconsistent, and have not provided specific information regarding factors that may contribute to adjustment or maladjustment.

Previous research has generally shown that illness-related factors may not impact psychosocial adjustment unless physical limitations are significant. Family context factors have been shown to play a significant role in terms of effects on children's own individual adjustment, particularly caregivers' stress. Finally, children's personal resiliency is believed to serve a protective role in terms of children's psychosocial adjustment to cancer, but this has yet to be proven in the literature. Due to the lack of research or conflicting findings in these areas, this study sought to clarify these relationships. Goals of the present study included evaluating the psychosocial adjustment of children with cancer as rated by caregiver and child, as well as the extent to which the following variables may be related to such adjustment: physical functionality as rated by caregiver and child, severity of illness as rated by medical professional, stage in treatment, relapse status, frequency and difficulty of parental

distress as rated by caregiver, family psychosocial risk as rated by caregiver, and child resiliency as rated by caregiver and child.

Children were eligible for the study if they had any type of leukemia or lymphoblastic lymphoma. Despite this relatively broad categorization, a vast majority of patients who presented to the data collection sites were children with ALL. This is somewhat to be expected as ALL is the most common form of childhood leukemia, affecting 73% of all children who have been diagnosed with leukemia (ACS, 2007). Only a small number of children with AML or lymphoma were identified, and no children with chronic types of leukemia were identified (e.g., CML). Thus, results may be most applicable to children and families coping with adjustment to ALL. Children ages six to 18 were eligible for participation, and results indicate a relatively even distribution across this age group, with a greater number of adolescents (children ages 12 to 18) than younger children. Participants were evenly distributed across gender groups, and a wide variety of ethnicities were represented. In fact, this study provides information across a more diverse population than most previous studies. It also included data regarding a small number of Spanish-speaking families, which is virtually absent in the current literature.

Previous researchers have indicated the importance of obtaining data from multiple informants (Kazak, 1997). The present study included data from caregivers, children, and medical professionals. In the majority of research examining children's adjustment to chronic illness, mothers most often serve as caregiver informants, and this study sought to include other caregivers as well. Despite the fact that any caregiver was

eligible to participate in this study, a majority of the participants were still mothers; perhaps this is indicative of the role that mothers tend to play in the treatment of children with chronic illness. While previous researchers have indicated a need to utilize data from other caregivers as well, it is possible that mothers may be the best informants if they take the primary caretaking responsibility (Elliott Brown & Barbarin, 1996; Kazak & Nachman, 1991; Koch et al., 1996; Kolbrun-Svavarsdottir, 2005; McGrath et al., 2005; Quin, 2004). The downside to this is that mothers have also been found to demonstrate higher levels of parenting stress when caring for a chronically ill child (likely due to the caretaking demands), which may impact their ratings of child adjustment.

Psychosocial Adjustment

Based on current research suggesting that children with cancer demonstrate normative adjustment in comparison to healthy children, it was expected that participants would demonstrate a broad range of psychosocial functioning, but that overall findings would reveal positive adjustment (Drotar & Bush, 1985; Kazak & Nachman, 1991). Results suggested that children with leukemia/lymphoma generally demonstrate average psychosocial functioning in the areas of internalizing symptoms, externalizing symptoms, adaptive behaviors, and school problems as rated by both caregivers and children themselves. Broadly speaking, caregivers tended to rate their children as having more psychosocial difficulties in both internalizing and externalizing areas than children rated themselves as having. While there were children who appeared to demonstrate “Clinically Significant” or “At Risk” adjustment difficulties, these were a

minority of the overall sample. About 10% of the sample demonstrated externalizing difficulties as rated by caregivers and/or children. It should be noted that findings regarding the poor reliability of child-reported externalizing symptoms indicated that caregivers may be a more reliable source of information when it comes to these types of behaviors. Approximately 14 to 33% of the sample demonstrated internalizing difficulties across raters. However, these scales included ratings in the area of “somatization,” which can hold different meaning among chronically-ill populations. In the area of adaptive skills, 11 to 18% of the sample demonstrated difficulties in this area. However, it should also be noted that the internal consistency of child-reported adaptive behaviors was relatively poor. These findings are demonstrative of previous research reporting only a small subset of pediatric cancer patients who tend to have serious psychological difficulties (Patenaude & Kupst, 2005; Stuber & Kazak, 1999).

A number of regression analyses were performed in order to determine the extent to which scores on the caregiver and child reports of psychosocial adjustment could be predicted or were related to the frequency and difficulty of parenting stress, the psychosocial risk of the family, the severity of the child’s illness, the child’s physical functionality, and/or the child’s personal resiliency. In addition, psychosocial adjustment was examined as it related to several demographic variables, including the site for medical treatment, language spoken by the family, age of the child, age at diagnosis, gender, ethnicity, type of cancer, time since diagnosis, and staging.

Results indicated that samples across treatment sites were generally similar in terms of psychosocial adjustment, with children at UMMC-F reporting slightly better

adaptive skills. This finding may be representative of the fact that UTMDACC tends to treat children who have been diagnosed for a longer period of time, and whom may have received treatment at another site previously. Their cancers tend to be more advanced than primary care centers, such as UMMC-F, and they may have been removed from typical childhood activities for a longer period of time, thus impacting overall adaptive skills. However, it is also important to note that mean adaptive skills reported at both sites were within the average range in comparison to same-age peers.

Interestingly, despite recommendations from Garstein et al. (1999) and Wallander and Varni (1998) regarding examination of illness groups in a “mixed” or noncategorical model rather than a discrete one, results of this analysis indicated that AML and ALL groups presented with different psychosocial adjustment than children with lymphoma. However, it is important not to draw significant conclusions from the finding in the present study given the small number of lymphoma participants. The findings may actually be related to statistical factors rather than true group differences.

A majority of the participants in this study were reported to be within a “high-risk” staging category. Despite this, however, children in this level of staging reported themselves as having fewer difficulties in school areas. It may be that children whose cancer is “high-risk” have less participation in typical school activities, causing their ratings to reflect low levels of school difficulties. Or, perhaps adult expectations for children’s academic performance are reduced during their treatment, causing them to experience fewer “difficulties.” Caregivers also reported that these children had fewer externalizing behaviors and greater personal strengths in comparison to children in

“standard-risk” and “low-risk” categories. Perhaps this is a reflection of the “reordering of life priorities” among this group of children and families, as well as a possible indication that caregivers recognize, and may even admire, the personal strengths that children demonstrate in such a dire situation. Another possibility is a “flight to health;” that is, when family health stressors are significant, members may focus on the things that are going well as a form of cognitive dissonance.

Although there were only a small number of Spanish-speaking families who participated in this study, there is some evidence to suggest that children from these families may demonstrate more difficulties with adjustment than English-speaking families. This is also true for the broader examination of ethnicity, in that non-Caucasian children demonstrated greater internalizing and overall emotional difficulties than Caucasian children. It is interesting to note that these findings were all based on child self-report measures, perhaps indicating that children in ethnic minority families express more emotional difficulties than their caregiver’s report suggests. However, it is again important to note that mean adjustment for all groups was within the average range. There are several possible explanations for these results, one of which may be that it is understandably stressful in and of itself to live in a country where most people do not speak your language, coupled with the added stressors related to navigating a hospital system run in English. Spanish-speaking caregivers may have added anxiety related to advocating for their children and feeling out of control due to language barriers.

The child's current age, as well as age at the time of diagnosis, emerged as significant factors in predicting parenting stress and child adjustment. Both younger children and younger age at diagnosis were found to be related to poorer child psychosocial adjustment and increased parenting stress. These findings are similar to that of previous research, which has examined the importance of developmental stage during diagnosis and treatment (Magrab, 1985; Patenaude & Kupst, 2005). However, the direction of this finding is opposite previous findings, which have reported greater difficulties for adolescents than young children (Manne & Miller, 1998; Quin, 2004; Wallander & Varni, 1992). Data were analyzed to determine whether there may be an interaction between age at diagnosis and time since diagnosis, which may assist in further explaining the relationship with child adjustment. However, this interaction was not statistically significant above what could be explained by each of these factors alone. It may be that diagnosis and treatment at a younger age is more difficult for caregivers as they assume primary responsibility for decision-making, care-taking, and treatment adherence. In addition, we live in a society where health care is generally good, and people tend to live for quite a long time; when very young people are diagnosed with a life-threatening illness, it disrupts our understanding of fairness in the universe, particularly for caregivers of children facing these risks. Interestingly, children who are diagnosed with leukemia at a younger age generally have a better prognosis medically, but this does not appear to be comforting to their caregivers.

Finally, there was a significant effect for gender on caregiver reported emotional symptoms, with greater difficulties reported for girls than boys. This was unexpected as

previous literature has generally reported similar emotional effects for both genders. This sample generally demonstrated greater difficulties in internalizing areas than externalizing, and in both general and clinical populations, girls are at greater risk for development of internalizing difficulties. Thus, findings may simply be reflective of this relatively “normative” pattern.

Illness-Related Factors

Children’s physical functionality and the severity of their illness were examined as predictor variables in terms of their influence on child psychosocial adjustment. Neither variable was found to be statistically significantly related to adjustment. Reasons for this finding are relatively unclear. However, previous findings regarding these variables have been equivocal, with a moderate group of literature finding similar results (Apter et al., 2003; Wallander & Varni, 1992; Wallander & Varni, 1998). Specifically, it has been noted that the child and family’s perception of the child’s illness may be the most important influence on overall adjustment (Barakat & Kazak, 1999; Drotar & Bush, 1985). As a result, child and caregiver ratings on the PedsQL may be a better indicator than the medical personnel’s report on the SOIS. Regardless, previous research has indicated that illness severity may account for only 10% of the variance in adjustment (Barakat & Kazak, 1999); as stated previously, it may be difficult to detect such a small amount with the decreased power in this study related to small sample size. Examination of correlation coefficients indicates that there are noted relationships between these variables that may have been statistically significant with a larger sample.

One of the goals of the present study was to examine the factor of time to determine whether certain factors over the *course* of pediatric cancer treatment may impact children's psychosocial adjustment. Two of these factors were defined as "relapse status" and "stage in treatment." However, our results indicated that there was no statistically significant effect for either of these factors in terms of their ability to predict children's psychosocial adjustment. There are several possible explanations for this finding. While previous research has emphasized the importance of examining adjustment variables over time given the chronic nature of present-day pediatric cancer treatment, it is considered best practice to examine time through a longitudinal research design (Kazak, 1989). This study is cross-sectional in nature, and may not provide the same information in terms of predictive-ability.

In addition, as will be noted subsequently in the study's limitations, sample size was relatively small, limiting power. Perhaps with a larger sample size, group differences could have been detected. This is especially the case with regard to the variable of treatment status, as correlation coefficients approached statistical significance in this sample.

Another factor that may have impacted this variable involves the research procedure, which defined that eligible families should not be approached for consent to participate within the first two weeks of diagnosis. Both hospitals where data were collected specified that approaching families sooner than this was unethical and inappropriate. Thus, it may be that there are unique characteristics specific to this time frame that were not examined due to understandable procedural limitations. Previous

research has demonstrated that children and families do demonstrate a period of emotional difficulty at the time of diagnosis, followed by adjustment (Kazak & Christakis, 1996; Kupst, 1992). However, it has also been argued that families are not able to accurately rate emotional and behavioral factors during this initial period as they are generally in “crisis mode.” Therefore, responses provided after this time frame may still capture similar experiences.

Family Context Factors

Previous research has indicated that it is particularly important to examine both parenting stress and family system functioning concurrently for families with children currently on treatment (Streisand et al., 2003). Examination of these factors in the current study revealed that family psychosocial risk did not have a statistically significant direct effect on children’s overall psychosocial adjustment. However, in nearly all of the correlational analyses, relationships between family psychosocial risk and child adjustment approached significance, indicating that findings may have been statistically significant with a larger sample size.

In addition, parenting stress emerged as a significant factor related to both internalizing and externalizing symptoms in children. In addition, family psychosocial risk was related to parenting stress. Thus, the model that may need to be examined is: Family Psychosocial Risk → Parenting Stress → Child Maladjustment. That is to say, family-level psychosocial risk factors may have an indirect affect on children’s adjustment through the variable of parenting stress; as risk factors increase, so does parenting stress, and as parenting stress increases, so do child adjustment difficulties. In

the present study, it was not appropriate to examine a mediation effect as there was not a statistically significant relationship between Family Psychosocial Risk and Child Adjustment. However, this may be related to the limited sample size. Results of this study may provide a theoretical model to be examined in future research with a larger sample.

One possible explanation for the model described above is that children themselves are relatively shielded from the psychosocial risk factors measured by the PAT 2.0 (e.g., family financial difficulties, lack of social support available to caretakers, caretakers' beliefs regarding the child's illness), thus protecting them from a direct effect of these variables. However, these factors may weigh quite heavily on caregivers, adding to the stress already present as related to caretaking for a chronically ill child.

One factor that was not examined in this research was caregivers' own symptomatology related to anxiety and/or depression. Previous research indicates that caregivers may be at even greater risk for adjustment difficulties than their children (Apter et al., 2003; Barrera et al., 2004; Phipps et al., 2006; Vannatta & Gerhardt, 2003). It is unclear how these difficulties may impact child adjustment and coping, except through social learning theory, or changes in the caregiver-child relationship. Overall, results seem to indicate bi-directionality in that caregivers' stress and coping impacts that in the child and vice versa.

Child Resiliency

Previous research has indicated that children with cancer have demonstrated significant resilience in the face of chronic stressors associated with their diagnosis and

treatment. Results of this study indicated that such personal strengths were also related to decreased levels of both externalizing and internalizing behaviors, as well as school problems. Stated inversely, children's personal strengths were shown to be related to positive adjustment to their illness and other areas of daily life. These results are representative of the hypotheses provided in previous research regarding the importance of temperament and trait characteristics in predicting adjustment to a chronic stressor such as childhood cancer (Phipps et al., 1006; Wallander & Varni, 1998).

The question then becomes, how do we foster these characteristics in children who do not present with them at the time of diagnosis? Previous research suggests that relationships play a significant role in fostering intrapersonal strengths (Wyman et al., 2000). Perhaps, then, children would benefit from examination and strengthening of the relationships in their lives during this critical time period in order to draw personal strength for adjustment.

Impact of Parenting Stress on Caregivers' Ratings of Child Adjustment

The final research question asked whether parenting stress may impact how caregivers rate or "see" their children's emotional and behavioral adjustment. Results of this analysis indicated that this may be the case for observations of externalizing behaviors, but not internalizing behaviors. That is to say, caregivers' ratings of high frequency or difficulty of stress were related to high ratings of internalizing and externalizing difficulties in their children. When you compare these ratings to the child's own self-ratings, caregivers' ratings of internalizing behaviors were generally correlated with child ratings. However, in ratings of externalizing behaviors, parenting

stress assisted in accounting for an additional 15% of the variance between caregiver and child ratings. This may indicate that when caregivers are stressed, they perceive more externalizing difficulties in their children, such as hyperactivity or conduct problems. Or, perhaps when caregivers are stressed, children demonstrate more externalizing problems, but do not report these on self-report measures.

Strengths and Limitations

The present study demonstrates several strengths and limitations, both in terms of the response to review of the literature, as well as methodology. In examination of strengths, this study utilized multiple informants in order to obtain a more complete picture of child and family functioning. These informants included both mothers and fathers in an attempt to broaden an understanding of each of these unique caregivers. The study was theory-driven, utilizing a breadth of research knowledge by significant researchers in the field to inform research questions and methodology. Utilization of highly-regarded theoretical models assisted in providing conceptualization of the multiple factors involved. Data regarding these several variables were collected within one sample of participants, rather than breaking down conceptual models into small parts. Data were collected from an ethnically, linguistically, and socioeconomically diverse sample, providing information regarding children and families previously not available. This study also examines the factor of time through examination of changes across relapse and treatment groups. Finally, this study took a positive psychology approach, which is considered to be the future of clinical psychology in order to emphasize strengths, particularly among this incredibly resilient group.

In addition to strengths, the study also has several limitations. First, the sample size for the study was smaller than originally anticipated, leading to concerns regarding statistical power to detect group differences. Power analysis with the current sample size ($N=37$) revealed a 49% chance of detecting a correlation of 0.3. Thus, it may be that statistically nonsignificant results are a function of the small sample size rather than an actual nonsignificant finding. The cross-sectional nature of the study with a one-time completion of questionnaires prohibits examination of “predictor” variables due to concurrent assessment. A longitudinal design would have been more effective in drawing firm conclusions about directionality; however, longitudinal studies are difficult to conduct. In fact, most recommendations for future research indicate the importance of longitudinal or prospective studies, as well as use of comparison group designs, but there are several practical difficulties in conducting such research (Kazak, 1993). As stated previously by Kazak (1993), it is difficult not to “oversimplify [the] rich and complex relationships” inherent among variables associated with psychosocial adjustment among children with cancer and their families. Due to the limited power of this study, several complex relationships were just that, oversimplified. In addition, this study examined a wide age range of childhood oncology patients (6 to 18 years). There may be significant developmental differences that could influence results, which are not accounted for by the age-based normative measures. Finally, there is limited generalizability to other chronic illnesses as the majority of the participating sample had ALL.

Suggestions for Future Research and Practice

Results of this study provide several implications for future research and practice with pediatric oncology populations. While findings indicate that children with cancer generally demonstrate normative adjustment, there were children in this sample who reported (or whose caregivers reported) “Clinically Significant” adjustment difficulties. The BASC-2 proved to be a helpful measure in examining these emotional and behavioral features in order to distinguish children in need of psychological services from those who are generally coping well. In addition, it appeared to be helpful to obtain ratings from more than one informant when possible, indicating that both caregiver and child report together are most helpful in distinguishing those who need additional services. However, caregiver ratings are generally more reliable than child ratings for externalizing symptoms.

Other demographic factors may be helpful in determining which children with leukemia may be at greatest risk for the development of adjustment difficulties. Findings in this study indicated that females may be at greater risk than males. In addition, children who are diagnosed at younger ages may be at greater risk for adjustment difficulties than those diagnosed during adolescence. Finally, families of color, or those for whom English is a second language, may be at greater risk than Caucasian, English-speaking families. These findings have important implications for pediatric psychology practice with oncology populations, in terms of targeting services to those in greatest anticipated need. Specifically, this also highlights the need for

practitioners who are Spanish-speaking, and/or the availability of interpreters to assist psychologists in their work with Spanish-speaking populations.

The independent variables examined in this study may also be helpful in identifying patients and families at greatest risk for adjustment difficulties. It is important not to assume that when a child's illness is more severe or limiting, or when prognosis is more highly guarded, that this will predict poorer adjustment. At present, there is limited evidence to suggest that illness severity or physical limitations are related to clinical maladjustment. In fact, children were found to be particularly resilient in the face of their struggle.

Personal strengths were shown to be a protective factor in terms of adjustment, indicating that children who start cancer treatment with generally good skills in emotional, interpersonal, intrapersonal, family, and school areas will likely fare well. It will be important for future researchers to examine additional information that may assist in identifying ways to promote these skills in children who do not appear to demonstrate them at the start of treatment. Practitioners' time would be well-spent to work with children to develop strengths in each of these areas, which may serve as protective factors for them. Assisting children in focusing on interpersonal relationships with members of the different "rings" of Bronfenbrenner's model will be important: caregivers, siblings, teachers, peers, etc.

Family context factors are likely the most difficult to study in terms of their relationship with child adjustment, as there is a virtually constant change in the factors involved. However, results of this study indicate that it would be particularly important

to examine the following model: Family Psychosocial Risk → Parenting Stress → Child Maladjustment. If this model were to be proven, it would have important implications for the role of pediatric oncology social workers and psychologists in terms of direct work with caregivers, other family members, and the social support network for a family who has a child with cancer. Assistance with basic needs (e.g., food, housing, transportation), development of coping strategies (e.g., relaxation, care-taking breaks), and development of strategies around utilization of social network resources to the greatest advantage would be important. In addition, while this study did not analyze the psychological functioning of caregivers, it may be an important area for future research and practice. In fact, findings from previous research, particularly studies regarding PTSD or PTSS in caregivers of children with cancer, indicate that practitioners who work in pediatric psychology would likely benefit from experience and training in adult clinical psychology as well in order to provide direct services to family members in particular need. In addition to direct work with caregivers, results of the study indicate that caregivers would benefit from assistance from psychosocial team members in development of behavioral strategies to assist in parenting a child with cancer. If a child's behaviors are managed, this will likely reduce stress, improve parenting, and lead to continued behavioral management.

Many of the interventions that can be done with children and families facing these issues cut across cancer lines. It is important for professionals in pediatric oncology settings to provide families with clear communication about the disease, elements of treatment, and medical decision-making (Janes-Hodder & Keene, 2002;

Spinetta, 1982). During the initial stages with the family, it will also be important to talk with both the family and the sick child (depending on his/her age) about their needs, including financial, behavioral, and emotional needs (Janes-Hodder & Keene, 2002; Vannatta & Gerhardt, 2003). Mental health professionals can provide the family with the skills necessary to effectively manage affective, behavioral, and physical difficulties associated with treatment, and can help to locate financial resources to help defray costs (Janes-Hodder & Keene, 2002; Spinetta, 1982; Zeltzer, 1994). Families dealing with these issues will likely also need assistance with school re-entry issues and academic needs, especially when cognitive and growth late effects are an issue (Armstrong & Briery, 2004; Janes-Hodder & Keene, 2002; Mulhern, 1994; Vannatta & Gerhardt, 2003). Mental health services will also be helpful in coping with relapse, issues of quality of life, death, and bereavement (Spinetta, 1982; Vannatta & Gerhardt, 2003). Janes-Hodder and Keene (2002) encouraged families who are dealing with a cancer diagnosis to work with hospital professionals as a team; **it is probably a helpful model for hospital professionals to do the same with families.**

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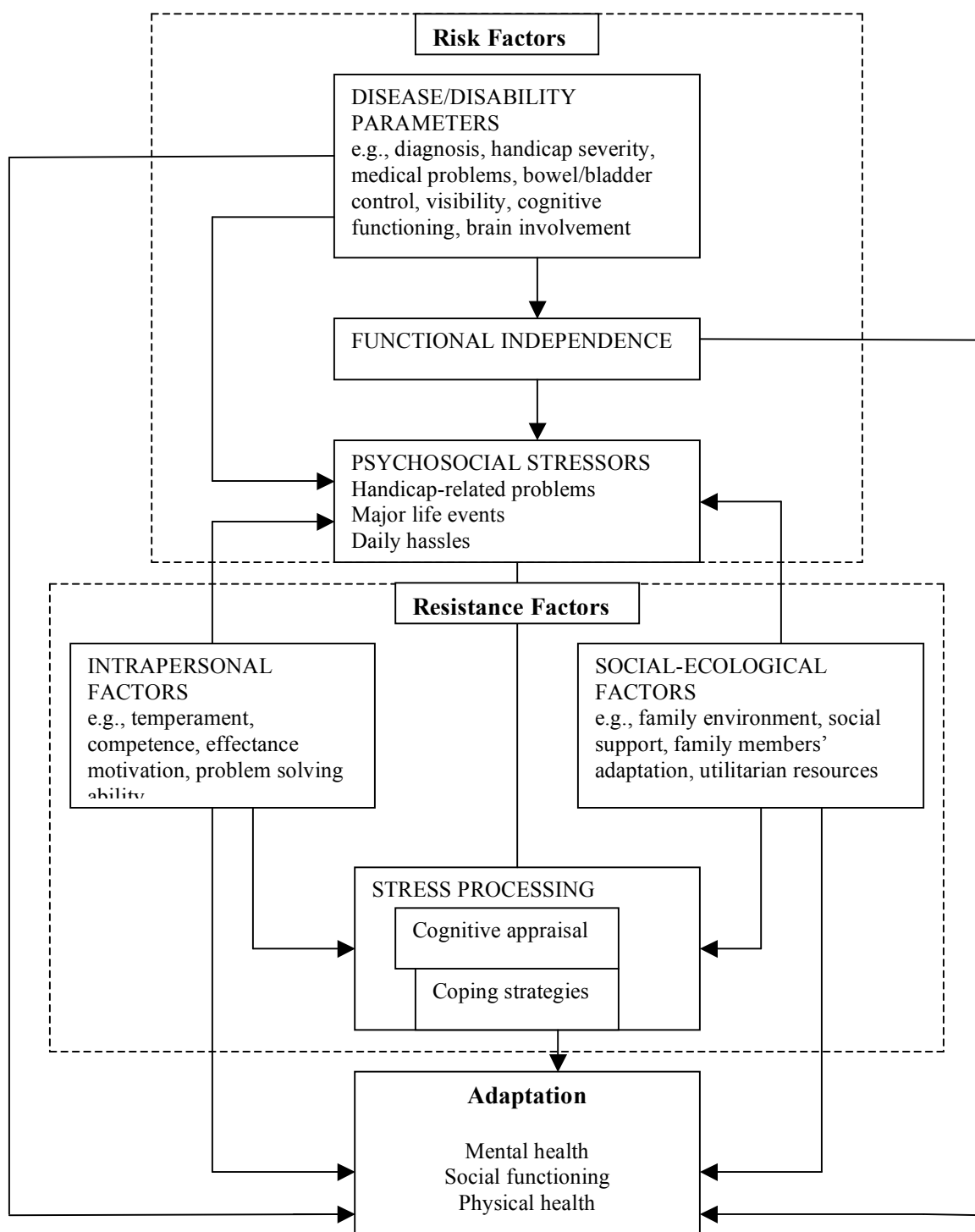
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¹APPENDIX 1¹ **Figure A-1.** Wallander & Varni's 1992 Disability-Stress-Coping Model

APPENDIX 2

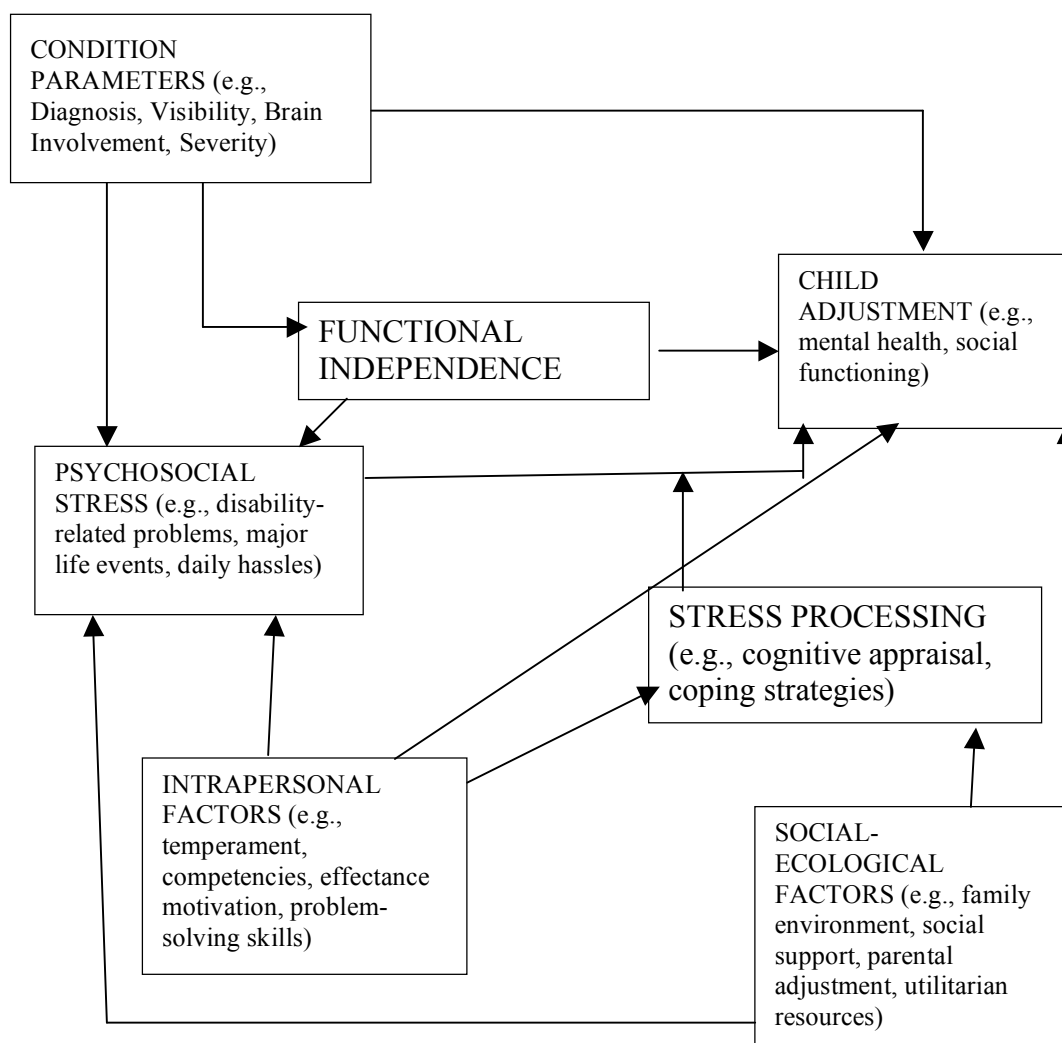


Figure A-2. Wallander & Varni's 2003 Disability-Stress-Coping Model

APPENDIX 3

Table A-3. Measures Completed by Each Participant

Participant	Measures Completed
Parent/Caregiver	<p>Psychosocial Assessment Tool 2.0 (PAT 2.0)</p> <p>Behavioral and Emotional Rating Scale – 2nd Edition: Parent Rating Scale (BERS-2-PRS)*</p> <p>Pediatric Inventory for Parents (PIP)*</p> <p>Pediatric Quality of Life Inventory: Parent Report for Children (PedsQL: PRC)</p> <p>Behavior Assessment System for Children-2nd Edition (BASC-2-PRS)</p>
Child	<p>Behavioral and Emotional Rating Scale – 2nd Edition: Youth Rating Scale (BERS-2-YRS)</p> <p>Pediatric Quality of Life Inventory: Child Report (PedsQL: CR)</p> <p>Behavior Assessment System for Children-2nd Edition (BASC-2-SRP)**</p>
Medical Staff Member	Severity of Illness Scale (SOIS)
Research Team Member	Demographic Form

* = English-speaking parents only

** = Children ages 8 and older only

APPENDIX 4

DEMOGRAPHIC FORM

Age: _____

DOB: _____

Grade: _____

Gender: _____

Ethnicity: _____ White/Caucasian/European-American
 _____ Black/African-American
 _____ Hispanic/Latino
 _____ American Indian/Alaska Native
 _____ Asian
 _____ Native Hawaiian/Pacific Islander
 _____ Middle Eastern
 _____ Biracial/Multiracial
 _____ Other

Person completing parental questionnaires—NO NAMES PLEASE (e.g., mother, father, guardian, grandmother, grandfather, etc.):

Medical Information

Diagnosis Date: _____

Type of Leukemia: _____

Staging: _____ Low-Risk
 _____ Standard-Risk
 _____ High-Risk

Presence of Relapse (Y/N): _____

If Yes, Number of Relapses: _____

Current Stage in Treatment (i.e., induction, intensification, maintenance):

Amount of total time spent in treatment (in years-months): _____

Age at diagnosis (in years-months): _____

Child is undergoing (circle one):

Standard medical treatment or Experimental medical treatment

Person completing medical questionnaire—NO NAMES PLEASE (e.g., physician, nurse practitioner, etc.):

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Newton, K.M. & Rae, W.A. (2005). Prader-Willi Syndrome. In S.W. Lee (Ed.),
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